

Recovery in Anorexia Nervosa: The struggle to develop a new identity.

**A Grounded Theory Study
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Abstract

This study aims to explore recovery in AN from the perspective of individuals who have experience of it and examine if there are implications for practice. A Grounded Theory methodology was used and semi structured interviews employed to collect the data. The sample consisted of 12 individuals who had experience of AN, either as currently ill or self-defined as recovered from AN. All interviews were recorded and transcribed and the constant comparison method employed to analyse the data.

The findings show that recovery for the person involves the successful integration of the four major dimensions of recovery; *deciding to recover*, *sustaining recovering*, *doing the necessary tasks* and *building a life without AN*. Each of these dimensions represents a series of tasks, which the person must complete, to varying degrees, if they are to recover. The grounded theory that emerged makes explicit that recovery from AN is conditional on the individuals' decision to recover and to take an active part in making it happen. Integrating the four dimensions is a spiralling process where the change in one is dependant on and is influenced by change in the others. They have to improve their physical condition or no recovery is possible because of the effects of starvation. They must tackle the issues that contributed to the AN and take on new roles if they are to move away from the AN identity. They must reconnect with others, asking for and accepting their help because

recovery is not achieved alone. If they invest the substantial physical and emotional energy needed to sustain their recovery then they are transformed. They explore and build a life separate from the AN through the integration of the four dimensions. As a result the limited identity of AN is replaced by a more complex identity where individuals are stronger, more connected with others and in control of their lives. This study supports greater attention to the role of self-development tasks and models of treatment that promote autonomy in the person.

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Chapter 1: Introduction

This study emerged from two sources: the first was my 15 years' professional/clinical experience and the second my engagement with the literature. In this chapter, I will outline how these sources came to influence the study. I will start with anorexia nervosa (AN), its severity and poor outcomes, and then highlight criticisms in the literature regarding recovery from AN, which include a lack of consensus around the nature of recovery. This will be followed by an outline of influences that constrain the measurement of recovery, such as including the voice of those with AN as well as the influences on professionals who work and research in the field. I will finish the chapter with a summary of what is demonstrated in the literature and the rationale for the study.

Anorexia Nervosa

AN is a debilitating mental illness with a suggested prevalence of 0.2% in young females (Hoek 1993). It has the highest mortality rate of any functional psychiatric illness (Nielsen et al. 2001) and 15% to 25% of sufferers are reported to be chronically symptomatic (Pike 1998, p.452). A recent review of 108 outcome studies in AN reported that around 45% of individuals recovered, 33% showed some improvement and approximately 20% remained in a chronic condition (Steinhausen 1999). A further review study by the same author (Steinhausen 2002) entitled 'The outcome of

Anorexia Nervosa in the 20th century' concludes that AN did not lose its relatively poor prognosis in the 20th century and that outcome has not improved over the second half of this century. This is a depressing conclusion for all affected by AN or involved in the care and treatment of those with it.

Regarding treatment, recent guidelines produced for the National Health Service (NHS) in the United Kingdom conclude that there is not enough evidence to determine which treatment modality is superior to others in the treatment of AN (NICE 2004). The guidelines go on to say 'there is no uniform or agreed approach to the psychological management of adults with AN, either in terms of types of treatment offered, their duration, intensity or the setting in which treatment is provided' (NICE 2004, p.81). The aetiology of AN is considered to be multi-factorial, with no single factor accounting for the development of the disorder in an individual or the variation in the disorder found amongst those with AN (Cooper 1995). The picture that emerges is that AN is a complex disorder, that outcomes are poor and that there is a limited evidence base to guide treatment decisions available to individuals, their families and professionals.

Some problems with the literature

No consensus

The National Institute of Clinical Excellence (NICE) guidelines for the NHS conclude that the 'overall body of research in the treatment of anorexia

nervosa is small and inconsistent in methodological quality' (NICE 2004, p.81). Pike (1998), in a review of the long-term course of AN, identified a number of methodological issues such as sample selection, length of follow-up, drop out, failure to trace, different diagnostic criteria and treatment effects, or lack of them, as all complicating efforts 'to summarise the findings of studies available'. She notes that the lack of unanimity in defining what criteria should be used to describe the various levels of outcome also hinders attempts at summary. Other authors (Berkman et al. 2007, Coutourier & Lock 2006, Noordenbos & Seubring 2006, Bell 2004, Tozzi et al. 2003 Steinhausen 2002, Jarman & Walsh 1999, Herzog et al. 1993) echo this. Deter & Herzog (1994) reported that the inclusion of measures of somatic comorbidity and psychological functioning in criteria for recovery lowered the rates from 54% to 41% when compared to physical criteria alone. Saccomani et al. (1998) produced a similar finding when they added psychological criteria to somatic criteria there was a reduction in recovery rates from 79% to 49%.

There are risks associated with any assumptions that can be made about study results in the absence of such a consensus. On one hand, Windauer (1993) cautions that 'good outcome' figures in the literature may be exaggerated if the literature focuses only on weight and menstrual status and the studies at the end of the last paragraph above provide some evidence for that. The author goes on to suggest that professionals may have to review their expectations for recovery in AN and accept that complete recovery may not be possible based on their findings. This is a

depressing conclusion and one unlikely to engender hope in those affected by AN. On the other hand, Herzog et al. (1993) reported that a group of participants in their study did not achieve 'total recovery' but did display a high level of social functioning. They went on to suggest that the absence of impairment in this area raised the question whether 'studies requiring a symptom free state for recovery may present an overly pessimistic view of these disorders (eating disorders in general) by not permitting the observation of less dramatic improvements in the course of the disorders' (p.45). This more optimistic view holds out the possibility of recovery whilst still having some symptoms of AN. Thus, a consequence of too limited a range of measures of outcome is that of either underestimating or overestimating outcome in AN. Strober (1997) found that although the physical measures of recovery were present after 4.7 years, the psychosocial measures took 6.6 years and concluded that recovery was a long process.

A further confusion that arises from the literature is the tendency for authors to shift between the words 'outcome' and 'recovery' as if they were the same thing (Couturier & Lock 2006, Finfgeld 2002, Lowe et al. 2001, Strober et al. 1997). An outcome, as defined by the Collins Concise dictionary, is 'something that follows from an action or situation; result; consequence.' The same dictionary defines recovery as 'the act or process of recovering, especially from sickness, a shock, or a setback' and 'restoration to a former or better condition...' There are clear differences between these two concepts. The former is a singular event that is the

result of an action and refers to a particular point in time. The latter, whilst including aspects of the former, also incorporates the idea of a process and other concepts such as restoration to a similar or better state. Using them interchangeably can lead to confusion as this links the two together and suggests that recovery, like outcome, is the result of a specific intervention, in this case treatment.

There are a number of issues with this view. First, it tends to ascribe recovery to the treatment intervention prescribed by the professional and portrays the individual with the illness as a passive participant in their recovery. Second, when an explanation is needed as to why treatment is not successful, the patient rather than the treatment gets the blame (I will return to this point later in the chapter). Finally, the existence of a number of explanations for the aetiology of AN prompts Jarman et al. (1997) to state that it is no surprise that there is no consensus in the definition of recovery given the 'diversity of theories regarding how best to understand and treat people with eating disorders' (p.138).

Limited measures of recovery

Until recently, studies on outcome in AN have tended to report on a limited subset of outcome measures (see Pike 1998 for review), and weight restoration and normalising eating behaviour were key measures of recovery (Noordenbos & Seubring 2006). As Jarman & Walsh (1999) argue, 'It seems that a clinically relevant definition of recovery from an eating disorder needs to encompass physical, psychological and social

dimensions of change' (p.777). Vitousek et al. (1991) are critical of the narrow focus on symptom status, particularly when asking the views of individuals identified as recovered. There is evidence from my clinical experience and the literature that questions such a limited focus when measuring recovery.

'It's not just about weight' was the response from one of the participants in this study on being asked what recovery from AN meant to her. The emphasis placed by her on this aspect of recovery demonstrates her feeling that there is too much focus on it by others. I know that it is often overemphasised, along with other physical measures, when assessing progress in the treatment of individuals with AN. Ratnasuriya et al. as far back as 1991 in a study looking at the outcome and prognostic factors after 20 years in individuals with AN found weight to be 'unreliable' as an indicator of outcome (p.500). The plea is for a broader understanding of the predicament these individuals find themselves in and to consider other aspects of the problem that are not so obvious. Bruch (1982) criticised treatment programmes that placed an emphasis on weight restoration alone and argued for the importance of psychological criteria in measurements of recovery. An overemphasis on weight was regarded negatively by individuals in studies looking at helpful and harmful aspects of their treatment (Shelley 1997b, Purgold 1987). Button & Warren (2001) reported that the greater the preoccupation with weight on the part of the therapist the more negative the experience of therapy by the individual with AN. They also reported that it contributed to increased dropout from

treatment. Colton & Pistrang (2004), in their study of what adolescents thought of their experience of treatment, noted that, although their participants unanimously endorsed the view that weight was important and needed to be addressed, attention to other aspects of their illness was also vital. Thus, from the perspective of the individual with AN, an appreciation of the broader aspects of recovery by others is important.

Constraints on measurement of recovery

In terms of the influences that constrain the measurement of other areas of recovery, one such influence is the way in which diagnostic systems work in psychiatry. As is the case with AN, diagnoses in psychiatry are based on a limited description of the disorder and ignore the more general impact on the individual. Hebebrand et al. (2004) are critical of this and argue that the criteria do 'not adequately describe the cardinal symptoms of this eating disorder' (p.827) and propose a revised set of criteria. Palmer (2003) summarises issues to do with the present classification systems, acknowledging their utility for clinicians and researchers alike but also highlighting their deficits and suggesting gaps to be filled. Key for this study, though, is the question he poses around diagnosis in the case of mental disorder:

'However it can be argued when the definition of mental disorder relies upon the mental state – as it almost inevitably should – that classification becomes more difficult. Can we really measure people's

thoughts and feelings reliably and is it reasonable to expect that they should fit neatly into categories? (p.1)

Hepworth (1994) notes that diagnosis is fraught with problems, especially 'in psychiatric medicine, where "illness" is not easily observable' (p.183). Ward and her colleagues (2003) note that even recent psychiatric diagnostic systems have not addressed this problem. A classification system that delineates specific behaviours and symptoms as indicating the presence of a particular disorder will identify the absence of these as representing recovery. One result of this is that recovery is equated to the absence of symptoms. This is likely to underestimate what is actually required for recovery, giving a premature suggestion that recovery has been achieved while leaving the individual with AN confused and dealing with the ongoing impacts of the disorder.

A further issue is the likely impact on treatment interventions and service configuration of the limited description of recovering from AN. As the aim would be to remove the signs and symptoms that reflect the diagnostic criteria then treatment and service delivery is likely to prioritise weight gain. Waller (1993) outlines that 'Therefore the focus of both clinical practice and research is on identifying the cluster of symptoms or behaviours – the diagnosis'(p.75) In the past, treatment programmes have been criticised for focussing on weight gain (Shelley 1997a, Bruch 1982) and how they achieved this. The 'one size fits all' approach that emphasises weight gain above all other goals obscures the individual needs of sufferers, promotes

unnecessary focus just on weight as a measure of recovery to the detriment of other interventions, and perpetuates the myth that restoring physical well-being will result in a cure from the illness. Shelley suggests that weight not be considered as a primary consideration in AN and highlights the psychological and social aspects that exist for the individual (Shelley 1997b). Such a view is supported by a study, which showed that individuals who had restored their weight still had many of the psychological and behavioural criteria associated with the disorder (Herzog et al. 1993). Some individuals with experience of the illness have written of the humiliation they felt because of these practices, condemning their inhumanity and ineffectiveness (Lawrence 1994, Hornbacher 1999). Vandereycken (2003) in an article looking at the place of inpatient care in the treatment of AN suggest that there is no consensus as to the when, where or how and that the development of evidence based practice is hampered by the paucity of research. Gowers et al. (2000) argue that the negative effects of hospital treatment are often overlooked in the research literature. They also raise the point that some of the features of those with AN such as low self-esteem makes these individuals particularly vulnerable to the negative effects of hospitalisation. Finally, Waller (1993) argues that 'Rigid application of diagnosis has contributed to the breakdown of the potentially valuable relationship between research and clinical practice' (p.86)

A second constraining influence relates to the leanings and the agenda of the professional undertaking the research. There have been attempts in

research to assess recovery using broader measures of psychosocial functioning but these are predetermined by the researchers (Windauer 1993, Hsu et al. 1992, Maine 1985). Pike (1998) describes a group of categories, which she labels 'psychosocial adjustment measures'. These include criteria such as marital status, having children, occupational status and level of academic achievement. She notes that adding these to measures of recovery will broaden the areas considered when defining outcome in AN. However, she remarks that it 'does not seem that these categories were examined qualitatively' (p.344). As a result, she recommends that 'the issue of general quality of life related to course and outcome in AN warrants further study' (p.446). Other studies also recognise the importance of psychosocial measures being included in the measurement of recovery (Pettersen & Rosenvinge 2002, Noordenbos 1992). Equally important is the professional's perspective on recovery from AN in terms of its likelihood to occur. If they are influenced by a particular view such as recovery from AN is not possible then their practice will be affected by this. It is clear that the literature on outcome in AN is pessimistic about the individuals chances. In addition, if the professional's perspective and that of the patients are different then this too can lead to difficulties as the two parties pursue different goals. As Jarman and Walsh(1999) state ' These alternative theoretical perspectives give rise to different recovery possibilities, and clinicians therefore need to be aware of the impact and constraints of their own and their clients' beliefs about the change process, especially if these are discrepant with one another' (p.782)

Another aspect of this is that in my clinical practice I observed that recovery is not widely discussed within eating disorders services. This seemed out of step with the stated aims and philosophy of those services which were about helping people recover from their AN. Instead, the focus was on weight, menstrual status and use of questionnaires that measured frequency and intensity of the individuals' eating disordered symptoms. There is a recognition anecdotally that other things are important if we are to measure recovery but these are not captured or observed in any structured way. Recently there has been a shift towards discussion of motivation to change and the use of motivational interviewing techniques. This shift in a way seeks to redress the neglect as it includes activities designed to access the individual's view of themselves in the future without AN. However, it does not enquire as to what would be involved to get there.

What influences the absence of the patient's perspective?

What might be some of the reasons for the absence of the patient's voice in the literature? The limited nature of the research available is one influence, (Strober 2005, Tierney 2004, Palmer 2000) and the literature's predominantly quantitative approach is another. A further influence relates to the description of AN as egosyntonic (Vitousek et al.1998) or 'maddeningly egosyntonic' (Strober 2004). Tan et al. (2003) describe 'egosyntonicity' as a phenomenon in which the individual experiences the AN 'as being a part of themselves or their identity' (p.537). Given this

characteristic it is argued that any observations made by the individual with AN must be treated with caution. The earliest descriptions in the literature of AN make reference to the attachment of the individual to the illness, a scenario not remarked on for other illnesses, and note the tendency for those with AN to deny that anything is wrong. In an early description of the an individual being treated for AN, Charles Lasègue eloquently conveys this idea 'Not only does she not sigh for recovery, but she is not ill-pleased with her condition' (p.151)

In more recent times Palmer and Treasure (1999), in an article on developing specialist services for people with eating disorders, note that individuals with AN do not readily adopt the sick role, have mixed feelings about treatment and avoid attempts at helping them change. The concept of ambivalence towards change in AN is well established in the literature (Geller et al. 2001, Vitousek et al. 1998). A study by Serpell et al. (1999) refers to the way individuals see their illness as both friend and enemy at the same time and highlights the need for this to be accommodated in providing treatment. Windauer et al. (1993) suggest that clinical efforts to tackle this characteristic patient ambivalence should focus on re-stating the resistance as a 'motivation issue' and utilising motivational enhancement principles to address the problem. Motivational enhancement techniques have been applied to the treatment of AN (Ward et al. 1996). However, fear on the part of the individual that professionals present a threat to their position is likely to result in behaviour that limits the impact of any intervention proposed. One way to address this could be by building a

relationship between the individual and helper with the characteristics of acceptance, empathy and validation (Newton 2000).

However, in mental health care, professionals are dependent on the self-report of the individuals who have mental health problems for information about and access to the difficulties posed by their mental health problems, as few are observable to the outsider. The existence of biological markers for many medical disorders and the fact that the identification of these becomes more sophisticated as technology progresses enables colleagues in the acute medical sector to cross-reference the symptoms reported to them with these markers. There are as yet no known markers for AN or for many other mental illnesses. As practitioners, we therefore depend on individuals to inform us about their internal experience in order to assess and judge how best to help. The earlier caution expressed concerning the value of self report is therefore worthy of some comment. The information provided by the individual with AN is needed to inform our interventions and to avoid operating to some extent in the dark. How, then, do we decide when to believe these individuals and when not to? This question has implications for employing qualitative methodologies with individuals with AN and other eating disorders. Thomsen et al. (2000) note that the psychopathology of those with eating disorders, particularly the skewed view of themselves and the world, poses a number of problems for qualitative researchers concerned with the trustworthiness and credibility of the studies undertaken with this population.

Vitousek et al. (1991) asked whether individuals with AN might give different responses to enquiries about recovery depending on how ill the individual was. The literature at this stage had little to say on this but there were related studies that responded to parts of this question. One study (Griffiths et al. 1998), of individuals' attitude to bed rest as a treatment intervention for AN, found that attitude to bed rest became less negative the further away they were chronologically from the event itself. The authors suggested that this was indicative of a change in attitude in the process of getting better, as improvement in condition was necessary to get off bed rest.

Related findings from studies, which sought the views of individuals previously treated, suggest that those with eating disorders do recognise the value of interventions that are compulsory when followed up later (Newton et al. 1993a, Cockett 1992). These findings support the possibility that participants may indeed report differently on their experiences at different times.

Vitousek et al. (1991) also address in detail the challenges of attending to the perspective of the individual with AN. They report that individuals

'Often refuse to concede that they suffer from a psychiatric disorder, deflect enquiries into the nature and extent of their symptomatology and decline attempts to assist them in recovering from it'. (p.648)

The authors list two other factors as affecting self-report:

1. The effects of starvation on an individual's reporting of their experience;
2. Personality factors associated with individuals with AN, particularly a desire to please others.

Vitousek et al. (1991) caution researchers about accepting at face value the reports of individuals with eating disorders. However, they go on to note that the researcher may be seen as a 'non-combatant' in the individuals' struggle with their treatment team and therefore not a threat to the individual or their current position. This perception of the researcher could facilitate a more open and honest discussion as the individual feels less pressure to conceal or hide aspects of their situation, which they believe would either upset others or draw an argument about change. Doing research with individuals with whom you also have a therapeutic role is ethically difficult, constrains the research relationship and militates against openness. (I will discuss this further in the methodology section.) In my local area, it was important that those with whom I had had direct clinical contact were excluded as participants from the study for ethical reasons as well as to prevent any confusion about my role. The findings above suggest that removing this confusion would lead to more openness in the research relationship.

The standpoint of the professional/researcher

Vitousek et al. (1991) raise the issue of the professional's belief system and its likely impact on interaction with an individual with an eating disorder. Pettersen & Roenvinge (2002) make the following point:

'It might be the case then, that when recovery from an eating disorder is defined only by clinicians and researchers, important aspects of recovery might be overlooked'. (p.62)

The professional's conceptualisation of causation and treatment will influence how the interaction proceeds and conceivably how effective it can be. The perspectives of individuals with AN and professionals are informed in different ways. The former have an intimate personal experience of the disorder and its impact. The latter have a more detached experience based on clinical and theoretical knowledge. Hepworth (1994) describes how the way in which a professional 'knows' AN has a major influence on how they relate to the individual with AN and what treatments the professional will suggest or prescribe. Surgenor and her colleagues (2002) suggest that it is of equal importance what the individual with AN 'knows' anorexia to be and how this relates to the self. The authors suggest that such 'knowing' will have a major impact on the individual's response to the treatment offered and their approach to recovery.

Within the literature, a collaborative relationship is most often associated with assisting the individual with AN towards recovery (Cockell et al. 2004, Button & Warren 2001, Jarman & Watson 1998). Given that a prerequisite

of such a relationship is a shared understanding of what work is needed, the dangers of the differing perspectives is clear. Noordenbos & Seubring (2006), in a study looking at patient and therapist perspectives on recovery, demonstrated agreements in some areas but found that patients identified 18 criteria for recovery as being more important than therapists' whilst therapists identified just three. The criteria identified by patients covered a range of areas, including psychological, emotional and social issues, whilst the therapists' three criteria were all in the area of somatic concerns. The authors conclude that 'more agreement about criteria for recovery between patients and therapists is not only necessary but also possible' (p.52).

Warnings expressed about undervaluing the voice of the individual with AN are important not just for clinicians but also for qualitative researchers, who must guard against the voice of the participant being overwritten by their own views. The methodology chosen, grounded theory helps address this and how it does so will be covered in the next chapter. Finally, Vitousek et al. (1991) caution that not asking for the opinions of those with AN carries the risk that the valuable contribution to be made by individuals with AN to recovery will be missed. The possibility is raised that professionals could be underestimating these individuals and 'that we stand to learn a great deal from our subjects if we can begin to ask them the right questions in the right ways' (p.663). This view is echoed by Maine (1985) who concludes her own study by suggesting that, 'In essence these results require that clinicians try harder than ever to listen to their anorexic

patients, for as this study indicates they know a great deal about what they need in order to recover from this life threatening illness' (p.54).

How accurate might individuals with AN be in reporting their clinical status? There is limited literature on this. Button and Warren (2001) in a follow up study of a cohort of individuals with AN 7.5 years after treatment found congruence between the assessment of 75% of their respondents of their recovery status and their corresponding scores on the criteria for judging recovery employed in the study. Ratnasuriya (1991) reported a similar finding. It is also possible that by not asking and not listening professionals run the risk of sending out a message that those with AN have nothing important to say or offer in their recovery and that individuals with AN must look to others for the answers they need. Such a message is likely to be experienced as disempowering when recovery demands the individual be empowered to increase the likelihood of change.

Returning to the issue outlined earlier in the chapter regarding explanations for lack of success in treatment, Pettersen & Rosenvinge (2002) note that

'One problem with clinical judgements is a fundamental attribution error which gives credit to the treatment for improvement and attributes treatment failure to patient resistance, manipulation or ambivalence' (p.61).

I know from my clinical experience that individuals with AN are often described as manipulative, particularly when it comes to reporting on anything related to their weight and food intake. One risk with such a description is that the professional, driven by assumptions about what 'anorexics' do, manipulating others as an example, seeks to avoid being manipulated by exerting more control over the treatment process. When a professional exerts control in this way a consequence is an undermining of the sense of control experienced by the individual with AN. Jarman et al. (1997), in a paper on the attitudes of professionals to this client group and how such attitudes influence treatment; describe this phenomenon as a psychological battle for control. The authors caution that a better understanding of the role control plays in AN is necessary if we are to avoid conflict in the therapeutic relationship. Button & Warren (2001) found that a sense of control was of central importance to participants in their study and recommend that, for treatment to be successful, individuals with AN should have as much control over the process as possible.

Pettersen & Rosenvinge (2002) highlight other consequences of this "fundamental attribution error", beginning with 'treatment conservatism' whereby professionals continue with unhelpful interventions because they blame the patient for the lack of success in treatment and not the intervention. Secondly, there is 'an underscoring of patient resources' (p.61) where the skills and ability of the individual with AN are ignored in the process of recovery from the disorder or are regarded as irrelevant. Thirdly, there is a 'failure to consider factors other than therapy in the

recovery process' (p.61) which ignores the possible contribution of friends, family and other non-healthcare related interventions in recovery. Treasure & Schmidt (1999) report that there is no good evidence on the prognosis of those with AN who do not attend formal medical care. However, Beresin et al. (1989) found that their participants identified interpersonal relationships as important to their recovery, but that these do not have to be part of a treatment process and can be with friends and family. Woods (2004), looking at untreated recovery from eating disorders found that the most frequent source of help cited by those who defined themselves as recovered was a helpful relationship with family and friends. Such findings raise questions about the need for the traditional professional–patient type relationship in the recovery process from AN. They also suggest that important aspects of recovery which participants can inform practitioners about are not picked up or are only indirectly identified by present research methods.

Noordenbos & Seubring (2006) pose the question as to whether individuals with eating disorders can fully recover or whether professionals involved in the field have to accept that these individuals will always be vulnerable to relapse or to retaining aspects of the AN. In response, the authors suggest that such a conclusion can only be accepted when individuals have 'received the best possible treatment and follow up care' (p.51). Therefore greater attention should be paid to the characteristics of the treatment offered, such as the skills and training of the professionals delivering the treatment, the appropriateness of treatment offered, the model of service

delivery, service availability or timing of the intervention. However, even these actions are likely to miss some of the factors that affect how treatment is experienced by the individual. Greenwood and colleagues, looking at satisfaction with psychiatric inpatient services and their relationship to patient and treatment factors, reported that two thirds of respondents to the survey reported adverse events whilst in treatment (Greenwood et al. 1999). Gowers et al. (2000) looked at the outcome of treatment for adolescents with AN and reported that inpatient treatment may be associated with poorer outcome and iatrogenic effects. Such experiences may have an impact on future healthcare choices made by the individual with AN. If treatments have been unhelpful, this is likely to influence the individuals' willingness to risk a repetition of the experience and lead to lower confidence in the usefulness of the treatment. I am aware from my clinical practice that individuals do have these types of experiences. Another concern is the impact of what might be described as a 'failed treatment' on the individuals and their families/carers. Such experiences could undermine the individuals' confidence in tackling the disorder whilst those closest to them may be disappointed or angry that initial responses to treatment are not sustained. Any of these will have implications for future treatment decisions as well as assessments of likely success or failure.

Parameters of the preliminary literature review

My first research proposal leant itself to a quantitative approach. I had collected data in the form of physiological measurements and questionnaires measuring the frequency and intensity of eating disorders and other symptoms. These were taken on admission and discharge from individuals who underwent inpatient treatment within an eating disorders service over a three-year period. My initial literature search, using the keywords 'anorexia nervosa', 'eating disorders', 'recovery' and 'outcome', was carried out in line with this initial proposal. Databases searched were CINAHL, Medline, Psychinfo, British Nursing Index, EMBASE, Allied and Complimentary Medicine and King's Fund.

As the study progressed, my engagement with the literature and my clinical experience combined to influence my decision to move away from the original proposal towards one addressing the perspective on recovery held by the individual with AN. I knew that the set of measures employed within the service were unsatisfactory because I saw individuals restore weight to a healthy level, display reduced intensity in symptoms as measured on the questionnaires, and then be readmitted some months later in need of further treatment. The altered focus in study prompted a change in research method and had implications for my relationship with the literature, which I will cover in the next chapter.

At this stage, my choice of grounded theory (Glaser & Strauss 1967) placed strictures on the scope of my initial venture into the literature. I had to make decisions as to what areas I would or would not engage with at the

start of the project. I planned to avoid the possibility of prejudicing my research through exposure to concepts of recovery in the literature, other than those, I carried myself, before I had collected and begun to analyse the data. However, I needed to refer to the literature to confirm my intuition that the perspective of the individual with AN was limited and to avoid the possibility of duplicating research already done. A further literature search was undertaken using the keywords as before but adding 'patient's perspective' and 'recovered individuals' as extra key words. This produced significant duplication of the original search but generated new studies as well. Some (for example, Garrett 1997, Hsu et al. 1992, Beresin 1989) were easily identified as being from the perspective of the individual with AN and were not read but were retained for the analysis section of my study. As my study progressed, I became aware of other studies from the perspective of the individual with AN (Weaver et al. 2005, Hardin 2003a, Tozzi et al. 2003). In grounded theory, an ongoing dialogue with the literature is seen as an integral part of the method. As these studies emerged during the analysis and the concepts arising from the data were at a stage when comparison with the literature was appropriate, I then chose to incorporate the studies into this dialogue.

Another group of studies emerged from the literature search in which researchers asked participants' views on the success and failure of treatment (Finfgeld 2002, Windauer et al. 1993, Lemberg & May 1991, Purgold 1987, Maine 1985). Some of these studies showed what individuals believed had helped them to recover from their illness, or were

reviews of other studies about influences on recovery and markers of recovery. The design of the studies, however, was usually in the form of a survey or a review of other studies. Such designs limit the information available to the areas covered in the survey document or the studies in the review. This does not allow for a 'thick' or in-depth description of the phenomenon in the study. Furthermore, the participants were chosen on the basis that they had completed treatment and were being followed up to assess their response to the treatments. Although treatments might have contributed to recovery and could relate in some ways to characteristics of recovery from their perspective, there was no attempt in the studies to describe either the nature or process of recovery in detail. I was interested in the individuals' experience of recovery from AN from their viewpoint and not only if they were recovered.

I decided not to review any of the literature in the general area of recovery from mental illness from the perspective of the sufferer at this point because this might have had a prejudicial effect on my data collection. Glaser & Strauss (1967) advise researchers not to be directed by the literature but to realise that their own data have priority.

There are other forces at work, which promote listening to those with experience of illness. In the NHS in the UK there is increasing pressure to include carers as well as those who are ill in all aspects of healthcare. The idea of including individuals with an illness and their carer in the care planning process is gradually becoming more acceptable, and recent

developments encourage involvement in service planning, design and delivery (DOH 1999a, 1999b, 1999c). Such involvement requires that professionals ascertain individuals' views on not just the treatment they need, or have had, but also their definitions of recovery or good outcome and goals for treatment. Asking individuals for this information should enable them to influence the focus of interventions at an earlier stage and so increase the individual nature of their care and treatment. Hanley (2000) highlights the challenges and benefits of such involvement.

All of these developments have arisen in the context of general medicine and have then been applied to the area of mental health. The obstacles that exist around the idea of the 'expert patient' in the acute sector are added to by the peculiarities of the mental health field. Issues such as capacity, informed consent, and the stigma associated with mental health problems and traditional models of practice have posed their own particular problems to practitioners in the mental health field when responding to these initiatives. Yet without these policy directives, such challenges may go unaddressed. The flow of resources will have an impact on service delivery models and those services that genuinely seek to involve users and carers may be rewarded for their efforts.

Summary

The literature therefore demonstrates that:

1. AN is a serious, debilitating illness and the outcome of treatment is unimpressive and has not changed in the second half of the twentieth

century. These factors pose a serious challenge to the concept of recovery from AN to professionals, individuals with AN and carers.

2. There is no consensus about the definition and measurement of recovery in AN which hinders progress in describing what recovery is, research into understanding recovery and the analysis of the existing literature.
3. Measurement of recovery has been criticised for focussing too narrowly on eating behaviour and weight restoration. Although more recently psychosocial criteria have been used to extend the measurements these have not often been studied qualitatively.
4. The voice of individuals with AN is present in a limited way and found mainly in the area of satisfaction with treatment received. Their voice is restricted to commenting on those areas predetermined as important by the researcher. There is an acknowledgement that too great a reliance on a professional perspective on recovery may lead to important aspects of recovery being missed. This lack of evidence is another restriction on the understanding of the nature of recovery in AN.
5. Individuals with AN often value aspects of the disorder and are ambivalent about accepting help. These characteristics have an impact on whether an individual with AN seeks treatment, how treatment is responded to and how treatment will or will not influence recovery from AN.
6. In the field of eating disorders, there is a dilemma as to how much to trust the voice of the individual with AN. Some authors suggest that the disorder means that the individual's view is less dependable and should

not be taken at face value when commenting on their disorder and its treatment. Others suggest that the individuals' contribution is essential and that we underestimate how important it is in recovery. This is also an important consideration for researchers employing qualitative methods.

7. Professionals working in the field of eating disorders have to be aware of how their own views and beliefs affect the interaction with the individual with an eating disorder if they are to better help the individuals recover. Again, this is relevant for the qualitative researcher.
8. In mental health, professionals depend largely on what people tell them of the experience of mental illness to determine what to do next to help.
9. An empathic, collaborative and affirming relationship is important in recovery from AN. This does not have to be with a professional and can involve family and friends. Achieving this can be hard for professionals particularly if the caution outlined in (7) above is not heeded.
10. Recent government policy within the NHS in the UK instructs professionals to involve individuals with illness in all decisions about care and in how services are to be developed. There are particular challenges to delivering this in mental health practice given the discrimination and stigma suffered by those with mental health problems.

Taking into account all of the above, my research question therefore addresses an area of need. There is a lack of consensus about the nature of recovery, and the limited presence of the voice of those who have

experienced AN impoverishes the understanding of recovery available. There have been few attempts to describe the process of recovery; the focus has been more on explaining how the individual got there or on describing the end state of recovery following treatment interventions.

This study aims to discover what individuals with experience of AN think about recovery and its meaning, to bring their thoughts, observations and beliefs to the literature, and to engage in a dialogue with it. To do this, a qualitative method will allow me to investigate in such a way as to capture the individuals' stories in as much detail as possible. However, I do not want just a description of recovery; I want to examine the data that emerges, compare it with the existing literature and search for explanatory concepts. With these, I can then identify any implications there might be for clinical practice and use these to suggest changes or modifications that will be of benefit to those who present for care and treatment for AN. How best to achieve these aims and to ensure that the outcome would be credible to colleagues and participants alike became the literal starting point of this study.

Research aim

The aim of the study is to explore recovery from AN from the perspective of individuals who have experience of it, in order to develop a grounded theory and examine its implications for practice.

Chapter 2: Methodology

Introduction

The overall aim of this study was to understand the participants' view of recovering from anorexia nervosa (AN). To achieve this, the following objectives were pursued:

1. To gather accounts of recovering from AN from those with experience of the disorder;
2. To explore the ideas and theory emerging from the data collection in a systematic way;
3. To analyse the findings in relation to the data and the existing literature in order to develop theory;
4. To identify potential implications and evaluate them in relation to clinical practice.

These objectives are related to the nature of the task I wanted to undertake and influenced the choice of how I went about the research. In this chapter, I will outline my choice of research paradigm and research method. I will also provide a detailed description of the research process to allow the reader to track my direction and to address some of the criticisms directed at the methodology. The data collection method and process will be outlined, as will the data analysis. However, I begin this chapter with a discussion of the ethical issues that arise when undertaking research in general and some, which were specific to the context of my study.

Ethics

A researcher is required to address very specific ethical, safety and confidentiality issues. This is even more pertinent when the participants in the research are vulnerable, as was the case in this study by virtue of their experience of AN. The vulnerabilities occur in a number of areas and arise because of the unequal power relationship between participants and researchers, concerns about capacity to consent, their position of needing clinical care, risk of harm and issues of confidentiality. The responsibility rests with the researcher to be aware of these issues and to act at all times in an ethical manner to ensure that no harm comes to those who agree to participate, including the researcher. They must also ensure that the research is appropriate.

Christians (2005) suggests four key areas that make up codes of ethics. The first of these is 'informed consent', which involves voluntary participation devoid of any physical or psychological coercion and consent that is based on full and open information about the project. The second is related to the first in that insisting on informed consent means that 'deception' has no part in social science research. The third is 'privacy and confidentiality' and relates to maintaining the anonymity of participants and protecting against disclosure of private information that could cause harm. The fourth relates to 'accuracy' and refers to the data being true to the sources from which it came and not contrived or false in any way. Outlined below are some of the steps that I took to address the first three of these issues. I will return to the fourth later in the chapter.

My past experience of being a participant in a study left me acutely aware of the vulnerabilities that can be experienced by participants. This emphasised for me how important the relationship between the researcher and participant is and how dependent the participants are on the researcher to protect them from any harm. Identifying and addressing possible causes of harm are essential in the research process and this was enabled through the process of securing ethical approval from the local research and ethics committee and my own organisation's research and development committee. These committees provided frameworks that encouraged me to consider the risks to prospective participants as well as myself and to develop interventions to remove or manage these. They also provided the assurance that the study would be reviewed by an external body, giving the opportunity to address possible problems with the proposal from the start. Initially, the process appeared daunting because of my anxiety about it and my inexperience concerning the system. However, as the process proceeded, my view altered to one appreciative of its role in protecting participants and me from any harm, intended or unintended. (See appendix A for ethics application form)

Informed consent

Smith (1992) states that 'The informed consent is considered to be one of the means by which a patient's rights are protected' (p.99) and as such is central to protecting prospective participants. Consent needs to be informed in that the individual has to be given enough information about the study and their role within it in order to make the decision. This is not

always easily achieved; in the case of this study where the topic was clear, the methodology chosen allowed for flexibility in terms of where the data might take the investigation. Thus, there were limits to informing prospective participants about the study in its entirety because it was not known at the outset. To address this, participants need to know that they can withdraw from the study at any time without any impact on their care and that there are support mechanisms in place should they need them. The study included both of these interventions partly for this reason and partly for others which I list elsewhere in this section.

Another important aspect of consent relates to the individual's reasons for taking part in the study. They must not feel coerced to participate for any reason, such as concerns about what impact a refusal might have on their care and treatment or feeling obliged to help a member of their treatment team. Equally, a decision to participate should not be because they anticipate more favourable treatment (Munhall & Oiler 1986). Given that I was undertaking this research in an area with which I was familiar, such considerations were particularly relevant to this study. Butler (2003) highlights a number of areas to be considered when undertaking research in your place of work, such as recruitment, data validity, data analysis and role conflict/confusion, and these are considered in relation to participants and colleagues.

As a first step, I decided that no individual I was in direct clinical contact with, or had been in the past, would be asked to participate in the study.

Through this, I hoped to reduce the risks of coercion to participate because of a wish to please me or to influence treatment decisions in a positive way. Equally, non-participation would carry fewer fears of having a negative impact on treatment. This decision, although necessary, excluded a large group of prospective participants by virtue of my significant therapeutic role within the local service. As such, it slowed the process of recruitment significantly and was one reason for adaptations to the study design outlined later. This decision also served to prevent any confusion arising as to what my role was in relation to individuals in the service because they did not have to decide whether I was their key worker or a researcher during meetings. Another advantage commented on by Vitousek (1991) was the likely effect on data validity given that the separation of researcher from treatment team increases the likelihood of participants being more open. In addressing Butler's concerns about data analysis, the fact that the study was not exploring any treatment carried out by the team or its outcome, I was under no pressure to analyse the data in a way that showed us in a good light.

There is another aspect to role confusion inherent in the clinician-researcher role, as discussed by Schutz (1994). She notes that the issue of concern is 'the establishment of detachment and objectivity' (p.413) and the 'transition from the previous role to that of the researcher' (p.413). The establishment of such objectivity is, in my view impossible, because I cannot separate myself from my experiences and knowledge of the field. More than this, I would not wish to do so because I believe it would

devalue the whole process. Because this also relates to my choice of methodology, I will address this question more fully in that section.

Notwithstanding some of the above, an information sheet about the study was prepared (see Appendix B). This sheet provided all the information about the study that prospective participants would need to assist them in making an informed decision about whether or not to participate. It included:

1. Advice to discuss the study and their participation with their GP as well as friends and family;
2. Guidance to a body independent of the organisation I worked for called Consumers for Ethics in Research (CERES), as well as to the National Health Service (NHS) in the UK in general, if they wanted further information about participating in research;
3. Details of myself, the organisations I was connected with and an offer to participants to discuss the research further with either my colleagues or myself;
4. An outline of what exactly they would have to do if they became involved in taking part in the study;
5. An emphasis on the voluntary nature of participation, the importance of consent and that refusing to participate and/or dropping out of the research at any time would have no impact to the care they would receive;
6. The issue of confidentiality and how this would be protected.

The last of these relates to another area of potential harm to participants: the handling of the information they provide whilst in the study. In my professional life, I am required to adhere to strict legal and professional guidelines on the handling and use of confidential information as produced by the professional bodies governing my professional life, my employer and government legislation (Nursing and Midwifery Council 2002, Department of Health 2001a, 2001b, Royal College of Nursing 2004). I saw no reason not to apply such standards to the handling of the information provided in this study. It was imperative that the prospective participants were guaranteed that they could not be identified in the data and that they were fully aware of what would happen to the information they provided and how it would be used.

To ensure anonymity, all participants were allocated a study number that appeared on the tapes and transcripts. Thus, the first participant was allocated study number 341, the next 342 and so on to 351. Later in the study, the quotes are followed by the study number to identify them. A list of study numbers with corresponding participants' contact details were kept separate from the tapes and transcripts. This was so that I could supply participants with copies of their interview transcripts if they wanted, to contact them for clarification or to invite them for a further interview. I removed any identifiable information that came up on the tapes when I first listened to them. The individual who transcribed the tapes lived out of the area in which the research took place. All participants were informed of the location and surname of the individual and asked if it caused them any

concerns about confidentiality. None did so. Participants were assured that any excerpts from their interview used in the study would be anonymised so that they would not be identifiable anywhere within the study or in any publications arising from the study. Finally, to ensure safe storage of the tapes and transcripts, they are kept in a locked box in a locked drawer to which only I have the key, either in my office at work or in my desk at home.

Participating in research always has a cost for participants, in terms of time, inconvenience or impacting on private events. Acknowledging this and the vulnerabilities of the participants outlined earlier, an important consideration for researchers is how to provide support to a participant should it become necessary. When individuals are asked to reflect on their experiences, bringing to mind information from a different time to inform the view they wish to share in the present, they may experience distress. Although the study was designed to explore participants' views on recovery from AN which, in my view, limited the scope for distress, I could not be certain. Therefore, participants were made aware of the following arrangements:

1. As a therapist, I would utilise the skills I had to assess the situation in the interview and immediately afterwards, and to monitor it for any distress. If any should appear, I would give immediate support and then work with the participant to decide on the next steps required.

2. Alternatively, or additionally, support was either provided from their key worker or another identified person, if they did not have a key worker at this time or preferred to speak to someone else.
3. My contact details were available to all participants and I could be contacted after the event to arrange support if needed.
4. Alternatively, participants could contact one of the support agencies for those with eating disorders in the community, details of which were provided.

All of the above were designed to enhance the protection of participants from any harm attributable to their participation in the study, both during it and after it was completed. They were also designed to address Christians (2005) concerns about informed consent, deception and privacy and confidentiality.

Methodology and Procedures

The aim of the study is to explore recovery from AN from the perspective of individuals who have experience of it, in order to develop a grounded theory and examine its implications for practice.

The subject matter of the study determined the choice of research paradigm and method. The initial choice of research paradigm was simplified by the characteristics inherent in quantitative and qualitative work. Elliott et al. (1999) describe the aim of qualitative research to be the understanding and representation of 'the experiences and actions of people as they encounter, engage and live through situations' (p.215). The

authors go on to stress that the understandings developed in the research are based as much as possible on the perspectives of the participants being studied. My motivation was to develop a better understanding of recovering from the perspective of those with experience of AN. Quantitative methods, with their emphasis on establishing causal relationships or exploring existing hypotheses, neither of which I had, were not suited to this research project. Bustin and her colleagues (1998) state that, 'Rather than taking a reductionist view of the subject in order that events can be measured, the holistic nature of the qualitative approach allows preservation of complexities, so that their nature can be explored and better understood' (p.197). Strauss & Corbin (1998) describe qualitative methods as an ideal way to gather data about phenomena that are hard to access using conventional research methods.

Streubert-Speciale & Carpenter (2007) highlight key characteristics emphasised by qualitative researchers, amongst which are the beliefs that there are multiple realities and that the researcher is an active participant in the research process. I referred to the latter previously when discussing the idea of role conflict while carrying out work in a familiar setting. Speciale & Carpenter then emphasise the issue of achieving objectivity and the transition into the role of the researcher. However, I do not believe that I can separate myself from my experiences. The ideas for this study emerged from just such experience and knowledge and I saw advantages to this being part of the process. Schutz (1994), in her article exploring the subjective approach in qualitative research, highlights that such

subjectivity is noted in the literature but is 'rarely acknowledged as a valuable aspect of the research' (p.413). She goes on to suggest that subjective experience and knowledge when working in a familiar setting can be advantageous in that 'one knows the parameters and can both work within them and use them to recognise valuable data' (p.414). This has some similarity with the concept of 'theoretical sensitivity' that I will come back to in the next section when outlining my choice of qualitative method.

I am aware that these experiences could affect the findings of the study through my pre-existing ideas or concepts about recovery coming to dominate the themes emerging from the participants' perspectives. However, the open acknowledgement of my prior experience allows me to be better able to put it aside during the process of data collection. In addition, by acknowledging it, I provide the reader of the research with an outline of what has influenced my position, thereby enabling them to consider this when making decisions about it. The key here is that qualitative methods fit best in terms of meeting the objectives of the study. In the next section on my choice of method, characteristics of the method, which are designed to address this concern with the researcher's impact on the data, are outlined.

Grounded theory

Of the qualitative methods available to be used, grounded theory (Glaser & Strauss 1967) seemed best suited to achieve all of the stated objectives of

the study. In common with other qualitative methodologies, the starting position for grounded theory is 'not to begin with theory and then set out to test it, but to begin with an area of enquiry and allow whatever is theoretically relevant to emerge' (Strauss & Corbin 1990, p.23). Meanwhile, Wimpenny & Gass (2000) argue that 'the generation of theory is the principal aim, to be achieved in the absence of an *a priori* conceptual framework or hypothesis' (p.1486). As I did not have an existing hypothesis to test and was interested in what recovery meant to the participants grounded theory seemed a good candidate. It also provided for the generation of a theory, which was another objective of the study.

Grounded theory as Cutcliffe (2000) notes, is 'rooted in symbolic interactionism wherein the researcher attempts to determine what symbolic meanings, artefacts, clothing, gestures and words have for groups of people as they interact with one another' (p.1477). Charmaz (2006) elaborates, stating that 'this perspective assumes that individuals are active, creative, and reflective and that social life consists of processes' (p.189). As a result of the above, grounded theory is able to both describe and explain the system or behaviour under study.

There are other characteristics of grounded theory, which support its selection as the method. Strauss & Corbin (1998) state that a grounded theory is 'one which is derived from data, systematically gathered and analysed through the research process' (p.12). Charmaz (1990) elaborates further, noting that it is the 'researcher's commitment to analyse what they

actually observe in the field or in the data' (p.1162) that results in the groundedness of the results. In this method, the researcher is required to synchronise the collection of data and its analysis, which enables themes and concepts that emerge to shape further data collection and theoretical development. This process is known as constant comparison and I will discuss it further in the data analysis.

One impact of this is that, as the research progresses, data collection becomes more focussed and specific (Holloway & Wheeler 2002). This systematic approach to data collection and analysis, combined with the developmental nature of the theory generation, is unique to grounded theory. This combination of flexibility, in terms of pursuing themes that emerge as the research progresses, with the structure of procedures to guide analysis, suited my study well. I have found it reassuring to have the guidance that is inherent in this approach to qualitative research.

A further strength of having such structure is that it helps to demonstrate what has happened in the research process so that readers can follow the route the researcher has taken. This is relevant in that it addresses the dependability of the research, which in turn, adds to its credibility. Buston et al. (1998) discuss the quantitative assumption of 'an unchanging world in which replication is possible, and support the idea of reliability as a measure of the quality of a study. In the qualitative paradigm, the notion of the social context always changing means that the concept of replication is flawed' (p.198). However, in pursuit of quality in qualitative research, the

authors go on to suggest that the researcher demonstrates dependability by maintaining a clear record of the research process and its outcomes to assist other researchers to follow an audit trail. A further advantage is that it enables a view to be taken on how the research procedures were followed. All of this adds to the credibility of the findings and enhances their acceptability.

A further concept in grounded theory relevant to the study's objectives is that of 'theoretical sensitivity'. Strauss & Corbin (1990) describe it as 'referring to the attitude of having insight, the ability to give meaning to the data, the capacity to understand and capability to separate the pertinent from that which isn't' (p.42). Holloway & Wheeler (2002) further note that there is a variety of sources for this sensitivity and that 'it can emerge from experience and reading built up over time' (p.156). In line with this concept, my 15 years' clinical experience and knowledge of the literature in the field of eating disorders are construed as positively contributing to the research process and would form a core of such theoretical sensitivity. In a sense, this makes a virtue of the experience and knowledge I bring to the research and acknowledges that these will have an impact on the data.

Preliminary literature review

I discussed the circumstances of the preliminary literature review in my introduction. This review was combined with my clinical knowledge and experience to produce the research proposal. As such, I think the review is more appropriately placed there amongst the factors that contributed to the

emergence of the proposal as opposed to its more traditional positioning within this section.

When reading the literature to help in deciding which method to employ, it emerged that there are a number of different approaches to grounded theory. Lack (2003) writes that this could be a characteristic of grounded theory's flexibility, with researchers adapting the original grounded theory method (Glaser & Strauss 1967) to the setting they are researching. Even the founders, Glaser and Strauss, have diverged in their views of what grounded theory is. Glaser (1992) has stated that the method proposed by Strauss and Corbin is not grounded theory but another method altogether. A number of authors discuss this divergence in views (Duchscher & Morgan 2004, Cutcliffe 2000, Hickey 1997, Melia 1996) and emphasise the differences, particularly the 'emergence vs. forced debate'. Duchscher & Morgan (2004) conclude that there are significant differences in the two approaches. As such, researchers should be clear which they are following if they are to avoid contributing to the erosion of grounded theory as a research method (Stern 1994). In this study, I followed the Strauss & Corbin model of grounded theory but agree with Lack (2003) that separating Glaser completely from the method is very difficult.

Participants

Choosing participants for a grounded theory study is usually guided by the principle of theoretical sampling. This sampling procedure is described by Glaser (1978) as being sampling driven by the data emerging from the

analysis, which guides the researcher to what data to collect next and where it might be found. Thus, the emerging theory determines the characteristics of further data collection and assists the researcher in developing depth in the data. However, my initial sample was determined by virtue of wanting to speak to individuals with experience of AN, which more closely resembles the concept of purposeful sampling.

Coyne (1997) draws attention to the confusion and overlap that exists between theoretical sampling and purposeful sampling, warning of the risks this poses to researchers. She describes the latter method as the identification of a group of participants who can provide the researcher with information about the central issues that are important to the aims of the study. Thus, the participants are chosen on purpose because of their special knowledge. It is clear from Glaser (1978) that, in the initial stages of a study, a researcher would seek out those who were in the best position to inform them about the phenomenon. From there, further sampling would be guided by the themes and concepts emerging from the data. Charmaz (2006) emphasises that there is a difference between this initial sampling and theoretical sampling, describing them as, 'Initial sampling in grounded theory is where you start, whereas theoretical sampling directs you where to go' (p.100). However, there is an inconsistency here – it would appear that my sampling strategy would be best described as comprising an initial purposeful sampling stage followed by theoretical sampling, a position shared with Lack (2003).

Another aspect of the sampling was that I deliberately chose not to focus solely on those who were recovered by excluding those who continued to have AN from the sample. I did this for a number of reasons but mainly because I was interested in recovery from AN from the individual's perspective. As discussed in the introduction, problems exist with both the under- and over-reporting of recovery in the literature, and this makes identification of a recovered group difficult. I would also be more likely to replicate the problem I was trying to avoid. Also, if I excluded those who were still ill from the study, it would mean that their perception of recovery would be missing from any theory that emerged, leaving it relevant only to those who had recovered and thereby limiting its use.

Including both those with the disorder and those who had recovered from it allowed for a greater range of data on the process to be collected. Including their views would also counter the charge levied at the literature in the introduction, that the interests of the professionals and academic researchers who carry out the research drive definitions of recovery. However, some caution is needed when including those who have AN in the sample. As discussed in the introduction, the 'egosyntonic' nature of AN calls into question the self report of individuals with AN, which poses problems for qualitative researchers who are concerned with the credibility of their analysis and findings (Bell 2004, Pike 1998, Vitousek et al. 1991). Vitousek et al. (1991) outline two other cautions: the impact of starvation on the capacity to participate in the study and concern that individuals with AN are overly compliant and eager to please. For outpatients, I attempted

to minimise the former by contacting interested participants' general practitioner (GP) to see if the GP had any objections to this on physical or psychological grounds (none did). For inpatients, I sought the views of the medical and nursing staff caring for the individuals prior to approaching any prospective participants.

Vitousek and her colleagues (1991) make suggestions as to how to deal with the two concerns they raise. They argue that the separation of the clinician and researcher roles can help. When the participant is discussing the AN with the researcher, 'some may even welcome such interactions as an opportunity to talk more about their experiences without incurring the risk that their admissions will be used in evidence against a defended position' (pp.655-656). The authors also suggest that participants who have AN have much to offer in terms of insights into AN and recovering from it. Thomsen et al. (2000), in addressing the same issue, suggest that the use of member checks is important. Researchers should ask participants to review emerging data and theory via follow-up meetings to see if it reflects their experience. The authors also suggest that researchers should discuss findings with colleagues who have experience in the area of study for a similar purpose. I undertook both of these steps. First, I had further meetings with four participants to seek their views on the theory that emerged and to see if it reflected their experience. Second, I shared drafts of the emerging theory with colleagues both within my own service and with colleagues elsewhere. I included the latter for two reasons, one to address any impact my position as an influential person

within the local service may have had on my colleagues and two to check that individuals with a different service philosophy would recognise the concepts emerging from the study. They all provided helpful comments. However, I was mindful that their comments did not dominate the perspectives of participants rather they supported continuing with data collection.

As a result of where I was recruiting, participants interviewed at both sites were initially in treatment for AN. As the interviews progressed, it became clear that the emerging data suggested interviewing individuals who described themselves as recovered as well as those who remained ill if I was to capture the process of recovery in detail. Questions that emerged included: Does recovery remain as difficult as initial participants suggested at the start do? Alternatively, did it become less difficult as recovery progressed? These questions could only be answered by those further along the recovery process or by those who had recovered to a certain point and had now relapsed to the extent that they required regular active treatment. Even in this case, a question emerges about what contributed to relapse from recovery. Equally, would those who were recovered describe their experiences differently as they would now have hindsight?

The sample consisted of ten women and one man. Such a ratio is in keeping with the reported prevalence in the population at large. Seven of the participants were recruited locally; the other four participants came from the extended area of the study. All participants were white and aged

18 or over. Given that the study was focussed on the perspective of recovery from AN by those with experience of the disorder, rather than comparisons between them, further characteristics of the sample were not required. For practical reasons, follow-up interviews were possible only with local participants, to which four agreed. As mentioned previously, these interviews were to explore concepts emerging in the data and to act as member checks to discover if they recognised the ideas and themes emerging in the study.

Recruitment

Strauss & Corbin (1998) note that, when a researcher is choosing a sample, they need to consider the practical implications of issues such as 'location of participants, how many there are going to be, resources available and the goals of the research' (p.204). Some of these issues are addressed in the ethics section, others are covered in this section, and the remainder are discussed in the section on data collection.

Initial recruitment took place from the eating disorders service where I worked and which served those in the local population aged 18 years and over. I began data collection in 2003 and, as noted earlier, the rate of recruitment was very slow. One response to this was to expand the area of recruitment to a neighbouring service, which also covered adults aged 18 and over. Locally, I discussed the study with my colleagues, emphasising to them the voluntary nature of participation. I then asked them to offer the study information sheet to all individuals with a diagnosis of AN, or atypical

versions of it, on their caseloads. There were no explicit exclusion criteria, aside from the individual being too physically ill to participate or being unable to speak or understand English. Given the slow recruitment, which I discussed with my colleagues, I became aware that some were excluding prospective participants for reasons irrelevant to the study, such as how good an informant they would be or length of time the person had been ill. Because I was interested in what individuals with experience of the illness thought about recovering, I spoke to them all again and asked that they offer all prospective participants a copy of the information sheet, which they agreed to do. I repeated the introduction to the study with the colleagues in the new area, and used my knowledge of the informal exclusion criteria adopted by my colleagues locally to avoid this situation happening again.

Data Collection

As suggested by Strauss & Corbin (1998), another area that guides sampling is the data collection methods to be utilised. To achieve the objectives of this study, I needed to capture rich descriptions of recovery from the participants. Interviews are a well-used method to achieve this. Kvale (1996) states that 'it should not be forgotten that interviews are particularly suited for studying people's understanding of the meanings in their lived world, describing their experiences and self understanding, and clarifying and elaborating their own perspective on their lived world' (p.105). There are a number of different types of interview and, in the literature; different names are given to similar interviewing strategies.

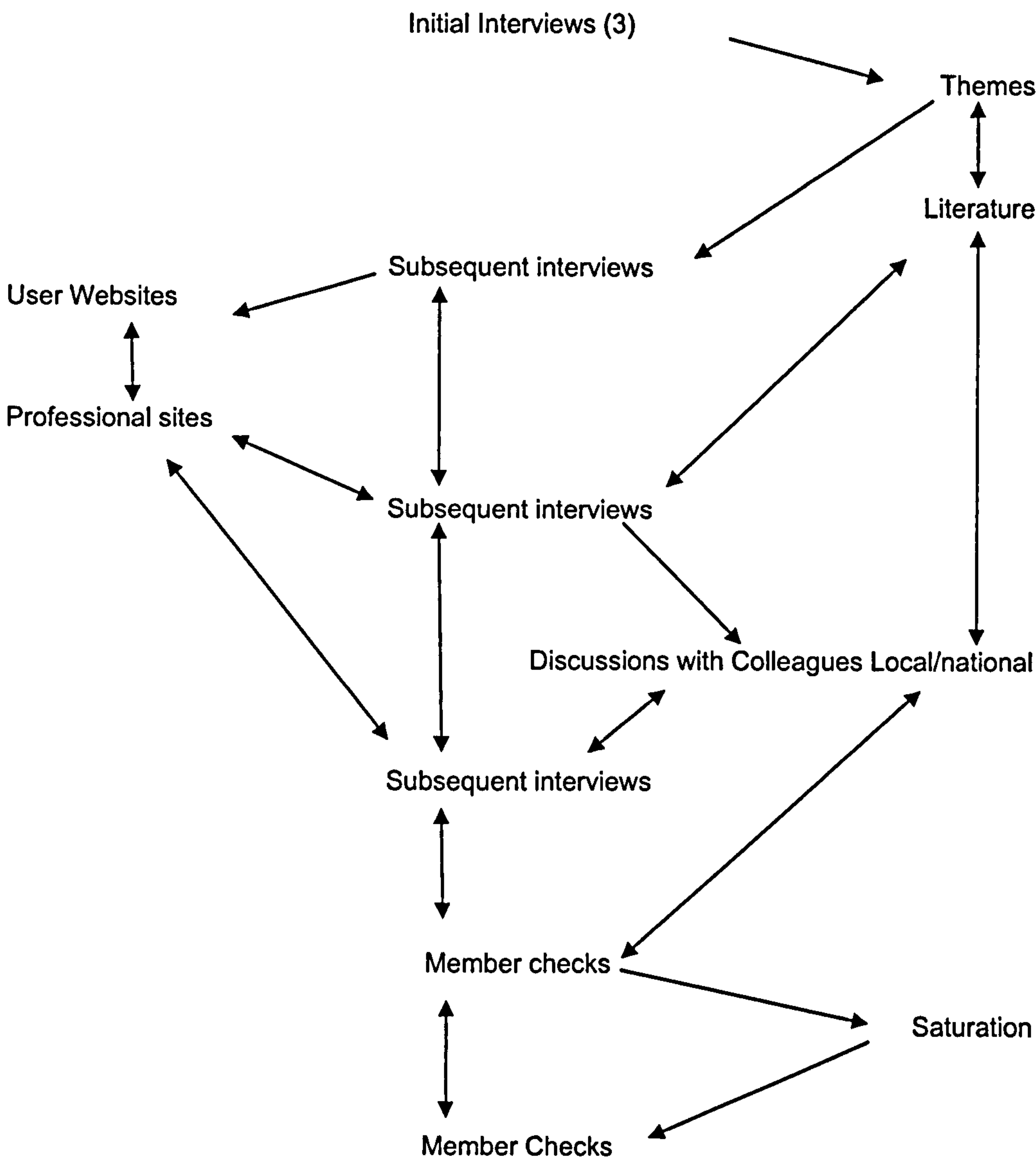
Wimpenny & Gass (2000) differentiate between structured and unstructured interviews, with the latter having a general guide for the interviewer. This resembles the semi-structured interview referred to by other authors (Holloway & Wheeler 2002) and best describes the approach I took. Interviews also provide the opportunity to clarify instantly issues that arise and allow flexibility in terms of time allocated to explore the same issues. I found these to be advantageous as I was able to pursue leads, which emerged with participants there and then as opposed to having to contact them again later. Therefore, in keeping with my objectives, I decided that a semi-structured interview offered the best means of data collection for this project.

In the quantitative paradigm, the sample size is linked inextricably to the concept of generalisability of the findings. Thus, the nature, number and characteristics of the participants are recorded to inform readers of the applicability of the study's results to other settings. There are criticisms of qualitative researchers whose sample sizes are regarded as being too small to provide generalisable results. As Elliott et al. (1999) point out; the root of this criticism lies in the different philosophies of knowledge generation subscribed to by qualitative and quantitative researchers. The size of the sample in qualitative research is small but the data collected generates what Geertz (1973) calls a 'thick description' of the situation or behaviour being studied. Such descriptions, with their depth and detail, offer different insights into the phenomenon being studied. I was seeking

this type of description but I was equally concerned with the development of theory and the acceptability of the results.

For this study the initial interviews following analysis, produced themes and concepts that were followed up in subsequent interviews. Figure 2.1 provides a diagrammatical representation of the sampling process.

Figure 2.1 Diagram of the sampling process



Uni-directional arrows indicate the direction of progress in the sampling process. Bi-directional arrows indicate a movement back and forward between these sources of data throughout the process and reflect the constant comparison of emerging themes and concepts with previous data to check for fit. Following the initial 3 participant interviews, which all came from within the local service I was guided by the emerging themes and the pace of the recruitment to seek participants from outside the service. This was designed to expand the perspectives on recovery to allow further exploration of the themes. Alongside this the literature I was engaged with also contributed to the guidance towards the next group of participants. A particular theme from the literature related to the existence of negative impacts of treatment on individuals with AN and this was not a theme apparent in the first three interviews. The absence of this theme made me wonder if the participants concern about their treatment was influencing their responses despite my efforts at allaying their fears in this area. Therefore the remaining interviews took place with individuals not in the inpatient setting although one of the member check interviews was with an individual at the end of their inpatient treatment.

Following the initial interviews subsequent interviews took place with individuals in outpatient treatment both with the local service and a neighbouring service. Alongside these interviews and in keeping with the themes emerging interviews were also carried out with those who described themselves as recovered. This broad range allowed the exploring of themes, particularly surprising ones such as recovery as

difficult and demanding to be checked as relevant and developed with those who were further along in treatment and recovered. The sample also allowed for other differences in perspective but which operated in the opposite direction to be checked. An example would be the theme of the necessity of weight restoration which emerges from those who are recovered and the professional literature. Would those still ill share this conviction? As it turned out they did and they added the sense of fear they felt about having to restore weight. This theme was then checked in later interviews with those who were recovered who confirmed they had had a similar experience.

Other sources of data were also accessed because of themes emerging in the research. These not only include the professional literature, such as journals and books, but also the literature written or contributed to by individuals with experience of the disorder (Pettit 2003, Hornbacher 1999, Hall 1993, Way 1993, Margolis 1988). Internet-based resources were accessed, including websites developed by organisations that represent the views of individuals with eating disorders and their relatives, (www.edauk.com; www.sweda.uk.org), as well as ones developed as information sources for professionals by professionals (www.eatingdisordersresearch.com). Recovery stories recorded on these websites provided not only resources to check the emerging themes but also questions to ask of the participants in the study. They also served to confirm saturation as visits to these resources did not produce new themes to those emerging from the later interviews in the study.

This ongoing interaction with the literature served to contribute to the development of the themes emerging, as well as supporting their relevance when similar themes were found to be present in the literature.

In grounded theory, the number of participants is not stated at the outset and interviews are carried out until the point of saturation is reached. The point of saturation is described by Charmaz (2006) as being 'when gathering fresh data no longer sparks new theoretical insights nor reveals new properties of these core theoretical categories' (p.113). Deciding when this point is reached is a challenge of using grounded theory and 'occurs at a different stage in each project and can not be predicted at the outset' (Holloway & Wheeler 2002, p.158). In line with the method, each interview was analysed for emerging concepts and themes. These in turn were compared with the other interviews, in looking for commonalities and differences. This process continued until no new concepts emerged from the data collected. For this study, this point was reached after 15 interviews, four of which were follow-ups with participants interviewed previously.

Procedure

Initially, the study proposal was to include a broader range of perspectives on what recovery from AN might mean. The proposal included individuals currently suffering, those who described themselves as recovered and their carers as participants. Individuals from each group were to have been interviewed on a one-to-one basis and then asked to participate in a focus

group once the initial data from the interviews had been analysed. As the research process unfolded, however, a number of events occurred that prompted a change in these arrangements.

1) Slow recruitment of participants

This was due to a number of reasons. The low incidence of AN in the general population means there is a small pool of available participants. This was further reduced because of my necessary decision to exclude any participant from the study who had been seen by me or was seeing me for treatment. This reduced the pool markedly because I had been the lead clinician in the area for the previous 10 years with a central role in the provision of treatment during that time.

2) Concerns over confidentiality

Another aspect was that some prospective participants expressed concerns to my colleagues and I about the involvement of their carers in the study. Colleagues who assisted in recruitment informed me that two individuals who did not participate expressed concern about the confidentiality of information should their carers be involved in the study.

3) Themes emerging

All of this was happening over time and early interviews were completed and analysed. Themes emerging from initial interviews raised suggestions that participants believed the view held by others about their illness and recovery from it were simplistic and superficial in nature.

I think some people have a very naïve perception of it and they just think it's a stupid young lady starving herself for no reason. (P344)

Holliday and her colleagues (2005), in a study comparing perceptions of illness between individuals with AN and lay people, found a marked discrepancy in how the two groups perceived the illness. The authors concluded that the difference was so significant that it could be contributing to the stigmatisation of individuals with AN. The early participants appeared to imply that others' perspectives lacked an essential component of the concept in which I was interested. For the reasons above, I decided to focus the study on individuals with the illness and those recovered from it, therefore removing carers.

Another issue that emerged from the recruitment process was the perceptions held by prospective participants about the focus group part of the study. These ranged from disliking the group format, believing that they would feel less likely to be open in it and fears about confidentiality. The initial design was to consist of four face-to-face interviews in each of the original subgroups. These were to be followed by a focus group in which the discussions would be guided by the themes emerging from the interviews. This would allow for further exploration of these concepts and serve as a check on the groundedness of the concepts through their endorsement by the group members. However, given that the focus group

was deterring prospective participants and that recruitment was so slow, I decided to adapt the design to the situation I had. The new design focussed on recruiting individuals with experience of the disorder to explore their perceptions of recovery on a one-to-one basis. It would no longer include a focus group. It did include the option of a follow-up meeting as a checking mechanism.

The proposed changes required;

- 1) Application to local ethics committees to remove carers and the focus group, as well as extending the geographical area from which I could recruit participants.
- 2) Research and development approval from the organisation that provided mental health care in the new area was also secured (see Appendices D & E for documents relating to these changes).

Ethical considerations relating to the extended area included ensuring that the safeguards in place for local participants were replicated in the new area in terms informed consent and available support structures. Alongside the more formal structures outlined above, I also met with colleagues working in the local eating disorders service to discuss the study and to see if the support could be delivered. I was fortunate to secure agreement to help in the recruitment process as well as delivering the same support package. I was also helped with the provision of interviewing space in the new area, which reduced potential problems with travelling for participants from that location.

The interview

I offered to undertake the interviews wherever the participant wished them to occur in order to offer the greatest sense of control to them and to reduce any anxiety they may have had about attending healthcare settings. I also wanted to avoid any influences that may have occurred from interviewing people in the location in which they were treated. Non-medical settings also helped to reduce any role confusion I might experience as a researcher. Most of the interviewees chose to meet with me on neutral ground, i.e. not at the eating disorders service buildings or their own homes; rather, another building such as a community mental health centre or general practice setting. Some explained their reasons for this, which included not wishing to burden family with reminders of the illness, not wishing to have a stranger in the house and not wishing to revisit places where treatment for the illness took place. I was grateful for their willingness to see me.

Wherever I was to see people, I arrived 30 minutes early to ensure the logistics of the interview were addressed in good time. Finding the room allocated, or changing it from a clinical space to a more informal one, and setting up and testing the recording equipment were completed before the participant arrived. I had an interview guide (Appendix F contains the original guide for interview number one) containing prompts to test the taping mechanism and to confirm consent to participate on the tape, along with some initial orienting questions. This guide was designed to aid me and was placed on a table to the side of the interview space so that I could

refer to it if needed. I also informed participants of its function. Over time, some of the questions on the guide changed to reflect the themes that emerged in the analysis and became progressively more focussed. The first question was always a broad one to open up the topic of recovery, by seeking what came to mind when participants thought of when they heard the words recovery from AN. Other areas covered included perceived challenges to recovering, support, their role and others roles in the process. These developed over time into more specific enquiries relating to more complex and specific themes, namely deciding to recover, recovering as a dynamic process, personal impacts of recovery, positives associated with being ill, dangers in recovery and strategies for recovering. Such changes are in line with grounded theory methodology as the analysis of the earlier interviews provides themes and categories that are pursued in subsequent data gathering.

The guide retained central questions such as the initial focussing question 'What ideas spring to mind when you hear the words recovery from AN' Themes which emerged and became questions in later versions of the guide included; breaking down the question about the role of others to explore family, friends and professionals separately. Also questions were added the addressed the concept of recovery as difficult and hard which further developed into questions about the process being a struggle. The concept of struggle allowed for questions about the nature of the struggle and that it was an internal as well as an external struggle to be taken up in subsequent interviews. Further areas covered were specific queries about

the benefits of the AN to the individual which allowed the emerging theme of the functionality of AN to be explored in detail. These changes also contributed to the emerging construct of 'wanting to recover' and 'having to do it for yourself and not others' This in turn lead to the theoretical ideas of 'Deciding to recover', and 'Making it personal' which are central to the basic social process which emerged in this study.

Other changes to the guide allowed questions about AN as being a part of the individuals identity to be explored and how recovery involved taking steps and tolerating the changes needed to replace the AN with other aspects of life. Questions were asked about what 'getting a life' meant and this allowed the role of expanding non "anorexic" activities to be highlighted. A further theme pursued through questioning but only with those who were recovered was the concept of the individual having been transformed by their recovery and becoming a "different person" in a sense more of a person than they had been before the illness. This in turn contributed to the theoretical concept of a change in identity being necessary for recovery to happen. This is described more fully within the findings section of this thesis. All of these changes to the guide were designed to pursue the themes emerging and to help develop in-depth descriptions and understanding of recovery. In doing this the theory which emerged could be seen to be grounded in the words of the participants. The interviews lasted between 40 minutes and two hours.

Before starting the interview, I reviewed the research process and aims with the participant, reiterating the option that existed for them to drop out of the study at any time should they wish. I also allowed an opportunity for any questions they may have had about the logistics of the interview or getting a copy of the transcript afterwards. I discussed the taping of the interview and checked for any concerns about the data storage. The interview proper began when I asked permission to start the tape recorder, recorded their consent to participate and made my first enquiry.

After the tape recorder had been switched off, there was time to check that the individual was all right and whether or not they had any questions or observations. During this time, one early participant volunteered the fact that she had never discussed the topic of recovery before in her contact with mental health services. She had discussed treatment and the reduction of symptoms but not what recovery was or how she felt about it. I was prompted to include an enquiry about this in future interviews because I found it surprising and wondered if this was a common experience.

I thanked participants for their time and ended the interview. Afterwards, I took the opportunity to review the interview and the interaction, noting down my own impressions and observations in my research diary. This diary also served as a journal in which early emerging concepts were written and in which memos were recorded; an integral part of data analysis in grounded theory. All participants were offered a copy of the transcribed interview and all except one asked for it to be sent to them. A

covering letter was included with the transcript asking participants to contact me if they had any concerns, questions or anxieties about the transcript or if they had other comments to make. None did so as a result of this letter.

When using grounded theory, a theory is being sought and therefore an ongoing dialogue with the literature is needed for comparisons to be made with existing data on the area being studied. It is in the role of the literature that I depart from the Glaserian position on grounded theory. Glaser (1992) argues that reviewing the literature prior to the emergence of theory grounded in the core variable can impede or contaminate the generation of theory. Strauss & Corbin (1990), on the other hand, advocate interaction with the literature to 'stimulate theoretical sensitivity, stimulate questions', and 'direct theoretical sampling as secondary sources of data and as supplementary validation' (pp.50-52). Hutchinson (1993) suggests that a preliminary literature review can identify current gaps in the literature and can help provide a rationale for the proposed research. This was the case for this study. Overall, my position is one in which the literature is viewed as a valuable contributing factor to the research process. The literature in this case refers not just to professional books and journals but also to the literature written by individuals with experience of AN and related mental health difficulties.

Data analysis

I listened to each of the tapes and then repeated this whilst reading the transcripts. I subsequently deleted any material that would identify individuals. Along with the interviews and the entries in my research diary, this process enabled me to become immersed in the data by becoming increasingly familiar with the contents of the interviews as recommended by the methodology. The gathering of data and its analysis in grounded theory is a dynamic and fluid process (Strauss & Corbin 1998). This process enables the data that is generated and analysed to determine the direction of further data generation and analysis. Hutchinson (1993) highlights that the process enables the researcher to change focus pursuing leads revealed by the ongoing data analysis. A strength of this analytic process is that the researcher can remain close to the participants and their words something I wanted to do.

The data analysis procedures of grounded theory are a constant comparison method and a structured coding process. Together, these require the researcher to engage in a process of crosschecking all aspects of the data and looking for patterns and processes. This maximises the groundedness of what emerges whilst minimising the risk of the author's concepts and ideas dominating the data. Another inherent protection is that the progressive breakdown of the data in the initial coding procedure is gradually superseded by the more complex techniques designed to reconstruct the data. This also ensures that the development of theory is grounded in the data. Hutchinson (1993) describes it as:

‘Grounded theory has an inherent safeguard against this danger [researcher’s ideas dominating] in that its explanation of key social structures and processes is derived from or grounded in the empirical data themselves’. (p.180)

Another component of the data analysis is the research diary. My diary served to capture the thoughts and ideas that emerged as I analysed and interacted with the data. Within the diary, I recorded memos, which are regarded as an integral feature of grounded theory. (Charmaz 2006) describes these as ‘the pivotal step between data collection and writing drafts of the paper’ and that they constitute a ‘crucial method’ in the theory by prompting early analysis of the codes in the research process (p.72). The memos reveal ideas that emerged as I analysed the data, comments on the development of initial concepts in the data and their grouping into categories, as well as ideas on the characteristics of these categories in terms of their dimensions and properties. They also contain initial theoretical ideas and questions that needed to be pursued in future data collection. Examples appear in Figure 2.2 and 2.3. The first relates to the dynamic interaction between, at this point the functionality and aversiveness of both AN and recovery from it. It was becoming clear that this interaction has a central role to play in continuing to recover. These characteristics were not only a part of the decision to recover but that the balance that existed between them could contribute to further recovery or relapse.

In some way the initial decision to recover had to be revisited and renewed if recovery was to continue or not as the case may be.

Figure 2.2: Example of a memo

How does the interaction of the emerging categories of the recovery process, the aversiveness and functionality of both AN and recovering impact on the process. These are dynamically interlinked and influence how the individual views recovering and of being able to cope with the demands of recovery. I think it has to be promoted from my original idea as a sub category of the recovering tasks to a major component of the theory that is emerging from the data. It helps explain how the weight restoration can undermine the whole recovering process because as the individual weight restores some of the psychological aspects that have been dealt with through the AN begin to surface. If I take as an example the experience of recovery as feeling like the individual's armour has been taken away then this may lead to an increased urge to return to AN. Participants have suggested that as recovery progresses the AN almost appears to increase in intensity in response to acting in ways which will improve their physical state but are contrary to the urgings of the AN. This interaction or feedback mechanism has an important part to play as it is part of the struggle described by participants with themselves about recovery. They act in one way to recover but a consequence is that they have a reaction to this which can be either supportive of further recovery or undermining of it. How the individual continues recovery in the face of this struggle is linked to the initial decision to recover but requires more than this as the individual is now faced with the demands of recovery which are difficult. Therefore the theory of recovering needs to incorporate an understanding of how the individual sustains recovery during the recovering process. Do they have to keep deciding to recover?

The second memo below describes the concept of guilt as it emerged from the study. In it I explore the concept identifying how it is experienced by the individual with AN, how the AN creates problems and how in recovering from AN guilt has to be tolerated. The memo also expands on the theme of the first memo identifying more of the properties of the category of sustaining recovery which emerged from the data.

Figure 2.3: Example of a memo

Memo. Guilt.

Eating, a necessary act of the recovery process contributes to the emergence of guilt. What might the guilt be about or related to? It would appear to be related to weight gain in the context of the 'anorexic' drive to avoid weight gain. However the individual has decided to engage in recovery and are likely to have reasons for doing so which can help with reducing the guilt. Participants talk about the guilt associated with spending time focused on themselves. Prior to the anorexia they tended to focus their energy on meeting the needs of others. An impact of the AN is that it allows them to focus on their own needs. In doing so they become more isolated from other people and focused on the small world of AN. So the AN whilst providing a solution for one problem also creates new problems to be solved. In the recovering process the individual has to spend time focused on their own needs and the cost to them is they have less time and energy for the needs of others. This is difficult to manage particularly as they see themselves as someone who helps other people. The guilt is also linked to the reasons for focussing on others in the first place. This can be related to low self esteem or not deserving to have the attention. If this is the case then acting against these perceptions could lead to feelings of guilt for neglecting others and/or expending time on themselves. The activity required by recovery contributes to the creation of an unpleasant emotional state that can increase the urge to return to AN. This implies that the management of guilt whatever its origins is essential to continuing to recover. More than this it appears that the management of guilt in a way that leads to its toleration and addresses the root causes of it is required as there are other means such as alcohol or drugs that may deal with the negative feelings but do not promote recovery. Another aspect of this may be, how does the individual address their emotional response to what happened when they were ill with AN. Does the process of recovering include the need for the individual to accept behaviours within AN which impacted on friends and family? Could it be that the individual by not recovering is attempting to avoid the consequences of their behaviour whilst ill including feelings of guilt? Are they in an indirect way dealing with the guilt by not dealing with it? It seems clear that guilt, in whatever shape will need to be addressed further with participants.

Also thinking about this reinforces a frequent characteristic of recovering emerging from the study that of the interaction of the activities of recovering with each other and how this can influence the recovering process. It appears that the impact is not only positive in the sense of promoting recovery but could be negative and lead to relapse. The factors that determine which it is seem to include the reasons why the person wants to recover, supports they have particularly if it is knowledgeable about AN, their expectations of recovery, confidence in their ability to recover and relationships they have. Other possible factors include social and work interests. There is a suggestion that expanding their non eating disordered life is also important. Further questions around the role of 'getting a life' as an early participant put it is necessary to explore this as is further information on how managing/tolerating guilt and more generally the aversive experiences of recovering from AN.

Open coding

Having immersed myself in the data, the more structured process of coding began with 'open coding'. Strauss & Corbin (1998) define this type of coding as:

'The analytic process through which concepts are identified and their properties and dimensions discovered in the data'. (p.101)

In this study, I utilised a line-by-line analysis of the transcribed interviews, examining each line in the document. Strauss & Corbin (1998) note that an advantage of line by line coding is:

'That it allows the analyst to generate categories quickly and to develop these categories through further sampling along dimensions of the category's general properties, through a process of sampling that they call theoretical sampling'. (p.119)

Concepts that emerged were written in the margins of the transcript and then onto a separate piece of paper, enabling easier comparison with the remaining data. It also allowed the concepts to be gathered into a smaller space. Given that the initial number of concepts for each interview was around 90 to 100, this facilitated their management. Figure 2.4 contains an example of this. Each interview was treated in the same way. Concepts were labelled using the participants' words wherever possible. Glaser & Strauss (1967) describe such labels as 'in vivo-codes'.

Figure 2.4: Example of concept gathering

Transcript excerpt	Line by line coding
The actual recovery – hard work. I think you start to recognise that there is a problem. The hardest thing is recognising there is a problem in the first place and then knowing the right people to go to, to ask for help. I went to my family first of all who then directed me this way. Um... but from my personal experience it's not something you can do on your own at all. I wouldn't have got to where I am now if it weren't for the support of my family. I think quite a lot of the way I've almost been sort of bullied into putting the weight on. I've done most of what I've done at home – I came to see CL here for a bit but most of what I've done has been done in my own time with my family support. Definitely without them I wouldn't put the weight on that I have.	Hard work Recognise problem Knowledge of right people Ask for help Ask family Being directed for help Personal experience Can't do it on your own Family support vital Wouldn't have progressed Bullied into putting weight on Treatment at home Saw a professional In own time Without family no progress

An example of such a code is 'a means of controlling things', which clearly conveys how this participant perceived her AN as a way of controlling other issues in her life. I also used labels that described the

meaning or imagery that participants wished to convey. An example of this is the label of 'Benefit of restoring weight'. This code captures what these participants meant in the phrases *'you need to gain weight in order to be able to do the other things in life'*, *'at low weight you can't really think clearly'*

In grounded theory, constant comparison is the key mechanism employed throughout the analytic process. Holloway & Wheeler (2002) describe it as the process of comparing 'each incident of a category with every other incident for similarities and differences' and that it is 'useful for finding the properties and dimensions of categories' (p.160). In this way, all new data generated are checked for their 'fit' with all existing data, and patterns or connections between them are more easily identified. This demands that the researcher constantly check that the emerging themes are grounded in the data. In this study, I returned repeatedly to the transcripts and then to the literature to ensure that this was the case.

The next step in the coding process is the grouping together of concepts into what are called 'categories'. Categories are described by Strauss & Corbin (1998) as 'higher order concepts' which 'have the potential to explain and predict' what is going on' (p.113). An example of a category in this study is that of 'dealing with underlying issues'. Participants identified a number of areas that existed prior to the illness taking hold and, in some cases, contributed to its development, which

would need to be addressed if recovery was to succeed. Examples include 'family stresses, 'low self esteem', 'putting yourself first' and 'painful issues'. I grouped these concepts together and created the category of 'dealing with underlying issues'. This category pulls together a group of activities, which the individual is required to address in the recovery process. It includes the idea that, without dealing with these, the process will be hampered. The identification of categories leads to:

1. The adaptation of the data collection methods to explore these criteria further (theoretical sampling);
2. Further analysis to begin to identify the properties and dimensions of the categories.

Strauss & Corbin (1998) described properties as 'the general or specific characteristics or attributes of a category; dimensions represent the location of a property along a continuum or range' (p.117).

Figure 2.5 illustrates the properties and dimension of a category from the study, that of 'Restoring weight' which I formed from the codes 'Outpatient weight restoring', 'Inpatient weight restoring', 'Rate of weight restoring' and 'Impact of weight restoring'. The general properties of the category (quantity, rate, method, location, tolerable and support for) are listed on the left whilst the dimensions (small or large amounts of weight required to achieve a healthy weight [quantity] and a slow or quick speed of weight restoration [rate] are listed on the

right. It is clear that the weight restoration is a complex concept. For illustration purposes, having to gain 6kg in weight to restore a healthy weight is perceived differently to having to gain 15kg. Equally where either quantity of weight is to be restored, inpatient or outpatient, level of support (high or low); will also influence how the individual experiences this process.

Figure 2.5: Category of Restoring Weight: Properties and Dimensions.

Properties	Dimensions		
Quantity	Small	↔	Large
Rate	Slow	↔	Fast
Method	Food	↔	Supplements
Location	Community	↔	Inpatient
Tolerable	Intolerable	↔	Tolerable
Support	High	↔	Low
	Informed	↔	Uninformed
Control	Total	↔	None

Axial coding

To progress the analysis, a higher level of coding, that of ‘axial coding’, began. Strauss & Corbin (1998) define this as:

‘The process relating categories to their sub categories, termed axial because coding occurs around the axes of the category, linking categories at the level of properties and dimensions’. (p.123)

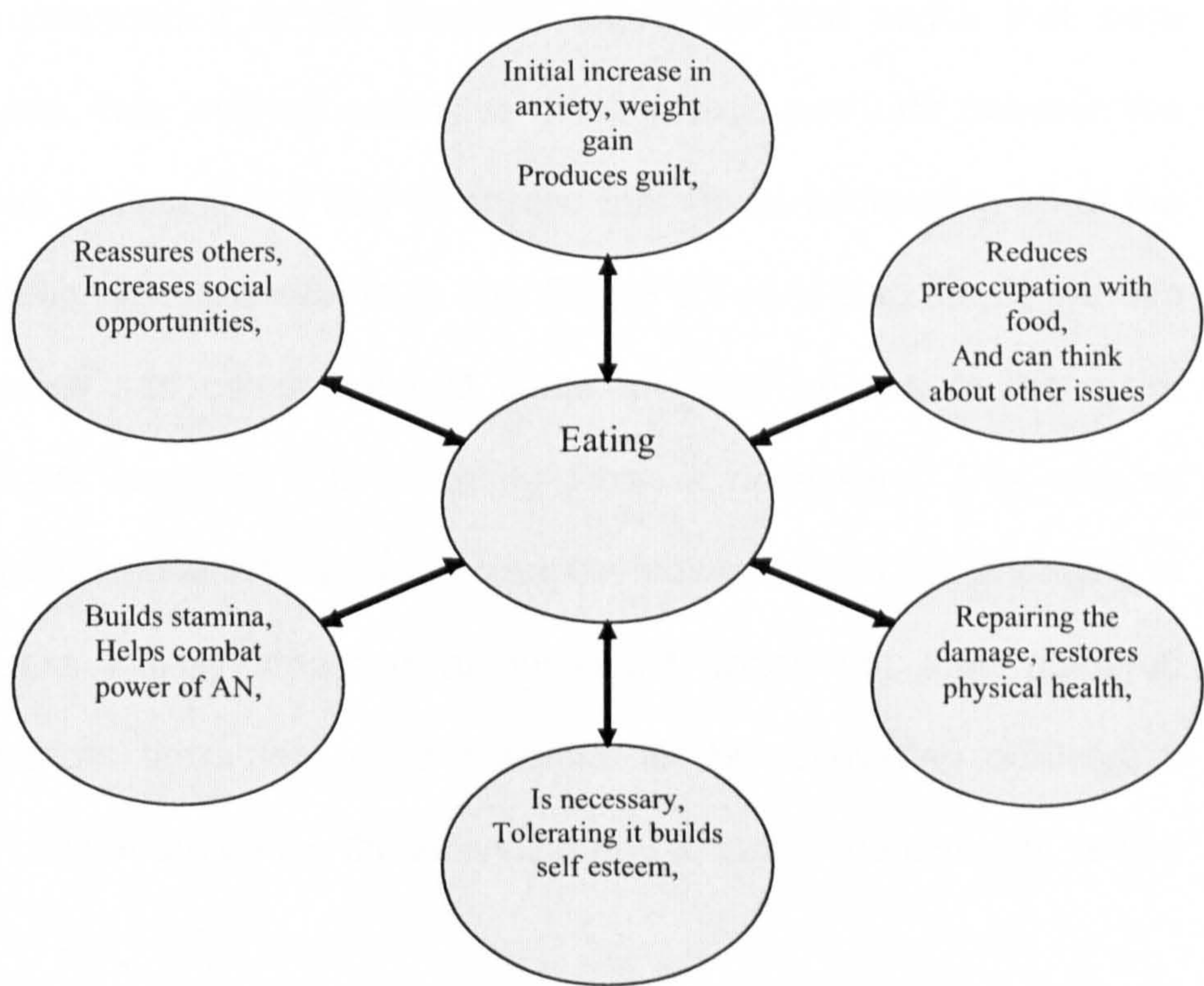
McLeod (2001) describes this type of coding as:

‘The identification of the conditions under which categories occur and the consequences of their occurrence [i.e. what follows them]’.

(p.73)

Therefore, I was looking to see how the categories ‘crosscut and link’ (Strauss & Corbin 1998, p.124). Figure 2.6 illustrates how the act of eating a code identified in the open coding period can be linked to the higher order categories and constructs. This diagram represents a more advanced stage of the analytic process as I drew out the connections that existed between codes and used these to build sub categories and categories.

Figure 2.6 Eating as a code and its links and connections.



As the individual with AN starts to eat more they are engaged with a number of aspects of their recovering. It is necessary to improve their physical state without it there can be no recovery. However the impacts of eating are felt emotionally, psychologically and socially and these impacts can either hinder or promote recovering. Thus an increase in stamina and a reduction in preoccupation with food may enable the individual to increase their social activity which in turn increases the support available from others to help sustain recovery. However if the eating is accompanied by increased guilt and anxiety which overwhelms the individual then relapse is likely. This process enabled me to begin to group the various codes and subcategories and increasingly to identify candidates for the major constructs that were emerging from the study.

When a possible candidate was identified I drew a diagram of it and then compared it to the available categories and codes that were available. This involved extensive moving back and forth between the sources of data that I had to ensure that I was addressing all of the information I had available to me. Figure 2.7 is a diagram of the subcategories and categories that came to make up one of the major constructs identified that of *doing what is necessary*. This was so labelled because the tasks involved the individual with AN engaging in the tasks initially identified as individual codes but then gathered together as tasks that were essential to the recovering process. It wasn't just about eating the individual had to tackle the disorder, retake

control of their life and deal with the issues that contributed to the development of the AN for recovery to be successful in the first place.

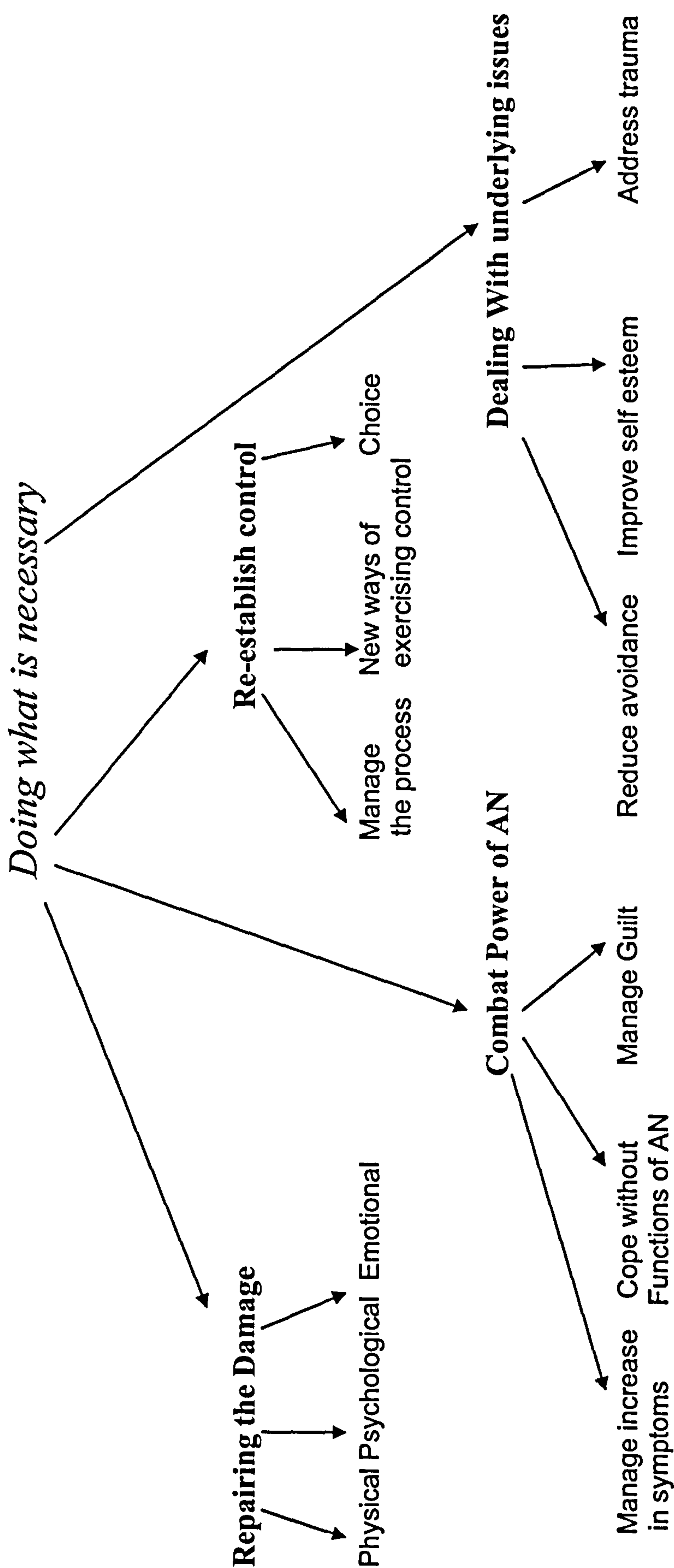
Through this analytical process of taking the codes that emerge and comparing them to all other aspects of the data I was able to build up the sub categories and categories which in turn lead to the major constructs. This process led to the development of the following four major constructs:

1. *Deciding to recover;*
2. *Undertaking the necessary tasks of recovering;*
3. *Building a life without AN;*
4. *Sustaining recovery;*

All of these constructs have a connection with the literature, which was part of the data analysis, in addition to surprising elements that are significant for this study.

To illustrate further how I developed these constructs and also the later levels of analysis carried out to identify the basic social process Figure 2.8 demonstrates the connections between the major constructs *deciding to recover* and *doing what is necessary* and also between the categories of these constructs Thus as an individual is *repairing the damage* they are also addressing the *limitations* imposed physically by the AN. However there is also recognition that if the individual continues to repair the damage then this will also help deliver on their *wanting to be more* by improving not only their physical state but also their emotional and psychological state.

Figure 2.7 Major construct *Doing what is necessary*



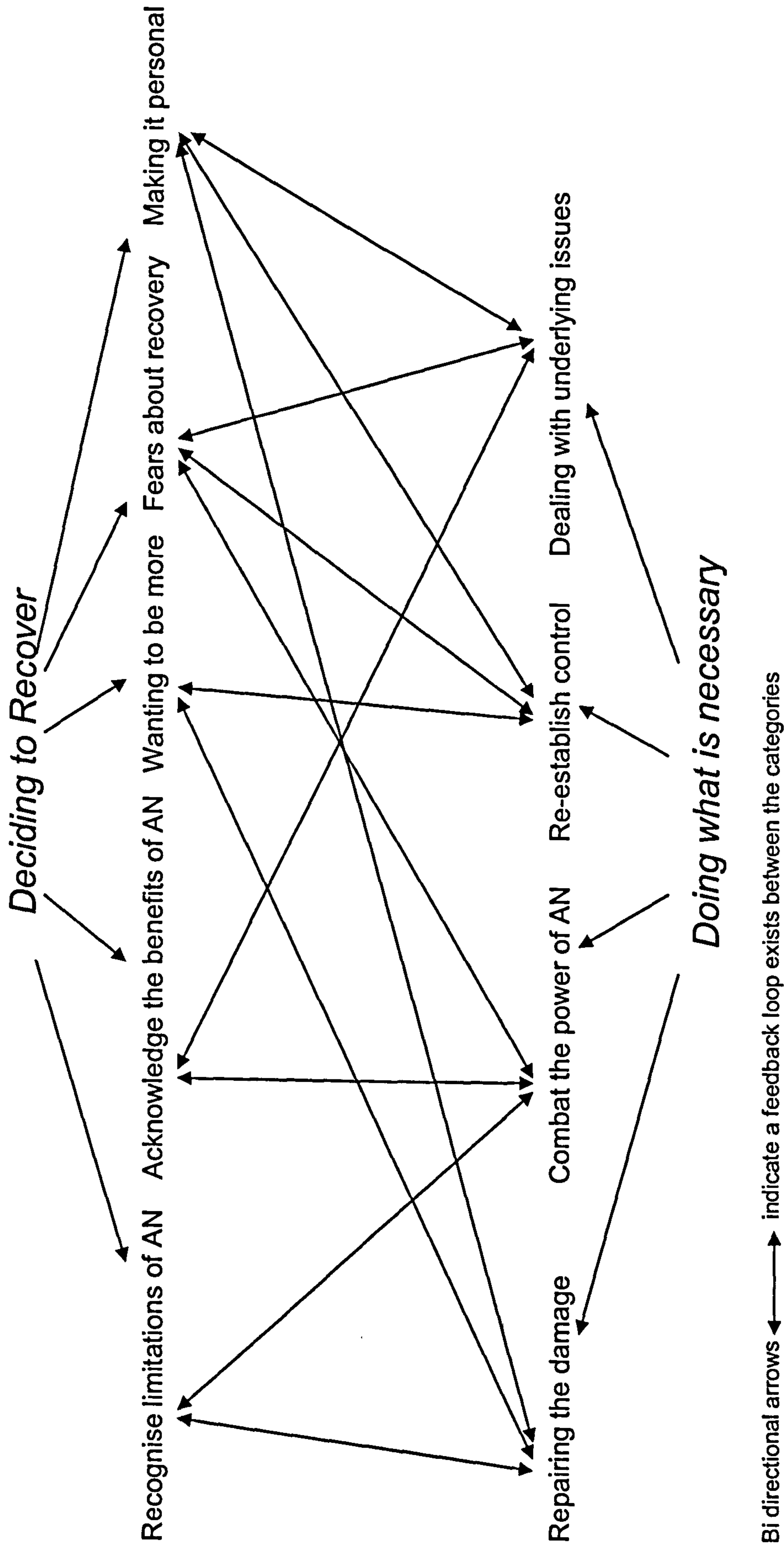
This in turn will contribute to their awareness of the *limitations* imposed by the AN. Therefore gaining weight, something identified at the open coding stage of analysis, is linked to the category of repairing the damage and through this to the major construct of doing what is necessary. Equally through this it is connected to *deciding to recover* and *sustaining recovery* because if the individual does not repair the damage e.g. restore weight by eating more, then the capacity to keep recovery going will be undermined. Another example is where the individual is able to recognise how the AN provides benefits for them. With this recognition comes insight into the power the AN has and also that the underlying issues managed by the AN will have to be dealt with. Figure 2.8 outlines just how interconnected these two main constructs were and these connections serve as the building blocks of the theory that emerged and as a guide to the data collection and analysis.

Selective coding

Strauss & Corbin (1998) described selective coding 'as the process of integrating and refining theory' (p.143). They also describe it as a process of integrating and refining the categories to generate the theory. It is selective in that the analyst has to 'select' a central variable that fulfils the following criteria:

1. It must be central; that is, all other major categories can be related to it.

Figure 2.8 Figure demonstrating how the major constructs of *Deciding to recover* and *Doing what is necessary* link.



2. The explanation that evolves by relating the categories is logical and consistent. There is no forcing of data.
3. The name or phrase used to describe the central category should be sufficiently abstract that it can be used to do research in other substantive areas, leading to the development of a more general theory.
4. As the concept is refined analytically through integration with other concepts, the theory grows in depth and explanatory power.
5. The concept is able to explain variation as well as the main point made by the data; that is, when conditions vary, the explanation still holds, although the way in which phenomena are expressed might look somewhat different. One also should be able to explain contradictory or alternative cases in terms of that central idea (p.147).

I subjected the data I had to further analysis using the list of characteristics above as a guide. Looking back at figure 2.8 it can be seen that the constructs outlined there have categories that convey the sense that recovering has both positive and negative characteristics and this is true of the other major constructs which emerged in the study. What emerged was a sense that the recovery process was sought after and yet feared at the same time. This was emphasised by participants in their descriptions, as the following examples show, with one participant using the word 'struggle' to describe their experience:

I'm the only one who can do it. It's a struggle with yourself.

(P348)

I know the bottom line is that it's a really funny illness – not funny, ha ha – but it's very strange because it's an illness and yet you want to have it and at the same point you have to make a decision that you don't want to have it any more. (P343)

The first quote is a bold statement about the struggle with the self; in the second it is clear that AN generates mixed feelings in the individual. Therefore, the concept of recovery as a struggle is conveyed by the data. There is a similarity here with the established concept of ambivalence towards recovery that is shown in the eating disorders literature (Gale et al. 2006, Cockell et al. 2002, Serpell et al. 1999). However, I would argue that this study is different because these previous descriptions were hampered by not ascribing enough importance to the concept of 'recovery as aversive'. One consequence of this was that the studies emphasised the importance of the benefits of staying ill for the individual. This, in turn, had another impact: that of suggesting that the individual hangs on to the illness because of what they gain from it. This opens the possibility of them being blamed for not getting better, as discussed in the introduction. However, in this study, the concept of 'struggle' embraces the sense of being engaged in an active process, of being drawn to and driven away from recovery at the same time.

Basic social process

Streubert-Speciale & Carpenter (2003) note that 'The discovery of a core variable is the goal of grounded theory' (p.115), whilst Holloway & Wheeler (2002) state that 'the researcher must discover the *core category* (p.160, emphasis in the original). This is the category that connects all other categories and the linkages are established in selective coding. It is also known as the basic social process which is described as 'a process that occurs over time and explains changes in behaviour' (Holloway & Wheeler 2002 p.160) I was drawn to the emerging idea of a change in the persons identity as a candidate for the core variable. This was because participants described a struggle with the AN identity during the recovering process. The process involved both reinforcing and aversive experiences to which they were exposed and how they came to deal with these provided them with information about themselves. The assumption that recovery had only positive connotations was incorrect for this group of participants. They perceived it has having a significant downside that could influence their decisions not to continue to recover. Thus, for them it could be a perilous undertaking. This is a difficult and perhaps surprising concept for professionals and family members alike who have been socialised to the idea that recovery, as described within our culture, is ultimately worth it. Yet clearly, those participants who were recovered were transformed by it. The increased self-knowledge and confidence they gleaned made them a better person and more able to manage the demands their lives placed on them.

Limitations of the study

Sample

There are a number of aspects of the sample that contribute to the limitations of the study. First, the sample was predominantly made up of women: with one male, the ratio was 10:1. As such, the study mainly reflects the views of women with AN. This ratio, however, reflects epidemiological information about relative prevalence and incidence of AN for men and women and is therefore a true reflection of the make-up of the group in society who have experience of the disorder. Nonetheless, to represent this group fully, additional male participants would enhance the applicability of the findings.

Second, the sample was aged 18 and over and was entirely white in its ethnicity. It is therefore limited in terms of the age range and ethnic diversity it represents. These two characteristics arise because the location of the study was within an adult eating disorders service and that service is within a geographical area where the level of ethnic diversity is limited. Further research could be carried out in a more multicultural environment as well as within a child and adolescent setting to address these limitations.

By using the interview as a method of data collection, as well as excluding those who do not speak English, the sample was biased towards those who could understand and speak the language of the researcher, in this

case English. Thus, a third concern is that the participants represented an articulate group who were able to verbalise their thoughts and feelings. However, the population who have the disorder share a similar profile and so it could be argued that the group is therefore representative of this population. Employing different data collection methods designed to overcome difficulties with language skill could address this.

Fourth, the sample was limited to individuals who had undergone treatment for AN. Despite some participants stating that they believed themselves to be recovered, all had been treated for the illness and their experience of such treatment may have created a bias in the results. According to Wood (2004), there are individuals with the illness who do not go for treatment and recover without it. Therefore, the findings may only represent the views of those with AN who have had treatment. However, the dialogue with the literature did incorporate those studies, which had researched those who were not treated, and they endorsed similar influences on their recovery as the participants in this study particularly increasing connection with others. (Wood 2004)

The sample size of 11 individuals also limited the study. In the methodology section, however, I argued that the sample size needed to be limited because the search for in-depth descriptions produces vast amounts of data. The fact that preliminary codes for the line-by-line analysis were running into approximately 100 per interview gives a sense of the data management task. In addition, total sample size in grounded

theory is determined once a point of saturation is reached and so cannot be decided on simply in terms of numbers of participants.

Another area of concern relates to do with the setting in which the research took place. How representative is it of eating disorder services elsewhere in the country. I outlined some of the factors above but others are relevant also. The service has evolved over the last 17 years into a specialist service offering residential, non-residential and community care and treatment for people with eating disorders. Throughout that time, I have played a key role in its development, and having a nursing background has influenced this process. I am the clinical lead and, as such, have infused the ideas that I gained in my training into how the service offers its care and treatment. One example of this would be the service's philosophy and policy on enforced methods of treatment. We do not offer any interventions that are forced and we very rarely employ any legal means to bring about compliance with treatment. This emphasis has influenced the training undertaken by members of the service an example of which would be motivational interviewing (MI). MI suggests that motivation to change is the result of the interaction between the two people involved in the interaction, in this case, the individual with AN and the healthcare professional and suggests ways of maximising this. This requires a collaborative approach is taken with both looking to produce a solution together and not as in traditional settings the professional as expert providing the answer. We are not a national centre delivering treatment across the country whilst engaged in ongoing research, as other centres in the UK are. Also we are

not a service that treats people with eating disorders within a more generic psychiatric setting, without a specialist service, as also occurs in the UK. Thus, the participants may reflect the nature and characteristics of our service to some extent. However, my recruitment from other areas and the contact with colleagues from other areas may mitigate some of these effects.

Chapter 3: Findings and Discussion

In this chapter, I aim to describe the findings, which emerged from the participants accounts and in line with the methodology discuss them in conjunction with the literature. I will outline the major constructs including their categories, illustrating them with quotes from participants. Throughout I will refer to the literature to compare the emerging constructs and to build a theory of recovering from AN. Then I will demonstrate the basic social process that runs through all of these constructs, that of 'developing a more complex identity' from the perspective of those with the disorder.

Participants suggested that their recovery was a struggle, involving a move from a limited sense of self as defined by the label 'anorexic' to a more complex identity which allowed them to engage fully with people and to take on other roles. To describe this better, I will take some license with the word 'knowing' and add to its meaning by including a more work-like aspect, alongside its more usual 'having knowledge of something'. Employing both senses of the word, individuals are literally 'knowing themselves better' (not ill) from AN through the knowledge they acquire during the recovering process. Thus the expansion of their life activities in recovery enables them to experience themselves as more than 'anorexic' which in turn acts as a spur to further recovery. However, this is a difficult task demanding commitment and the use of extensive personal resources to achieve. It has its dangers in that, for the individual to recover, they must

engage with activities that expose them to circumstances and emotions for which they are often unprepared. The insecurity and uncertainty of this period is in stark contrast to the predictability and routine of their lives when ill with AN. The resulting distress can lead to setbacks or lapses back into AN. As a result, participants describe recovering as a 'struggle' that has to be won, which involves those closest to them, their illness, sometimes professionals trying to help and, above all, a struggle with themselves to tolerate life without AN and to become more than they are.

Summary of the findings

In Table 3.1, is a summary of the major constructs and categories that emerged from the participants' accounts. This table is here to orientate the reader as to the major constructs and their categories and as a point of reference for the discussion that follows. What follows afterwards is a very brief narrative description with the same purpose in mind. Recovery from AN is a difficult and demanding task for the individual. It requires that the individual address the detrimental effects to their physical, psychological, social and emotional health in the process. However, it is more than this and individuals must recognise and let go of the aspects of AN that have come to serve a function for them. Functions such as avoiding emotions and being excused from life's responsibilities must be relinquished if recovery is to happen.

Table 3.1: Summary of the major constructs along with their categories.

Major Construct	Categories
Deciding to recover	<ol style="list-style-type: none"> 1. Recognising the limitations of AN 2. Acknowledging the benefits of AN to them 3. Wanting to be more 4. Fears about recovery 5. Make it personal
Doing what is necessary	<ol style="list-style-type: none"> 1. Repairing the damage 2. Dealing with underlying issues 3. Re establishing control. 4. Combating the power of AN
Building a life without AN	<ol style="list-style-type: none"> 1. Taking on new roles 2. Getting and using support from others
Sustaining Recovery	<ol style="list-style-type: none"> 1. Acknowledging the positives 2. Managing the negatives 3. Deciding to recover

The simplicity and certainty of life with AN provides a sense of control for the individual and they have to redefine their understanding of control so that they can embrace more healthy ways of controlling their lives. This means they may have to learn new skills in managing their emotional life, to expose themselves to novel situations, to face their doubts about themselves and their worth and to re-engage with others from whom they have become distanced. Initially, this is difficult and distressing, and relapse is always a possibility if the individuals' support mechanisms and

capacity to tolerate uncertainty are overwhelmed. Indeed, participants emphasised that the work of recovering was demanding and at times contributed to the urge to return to AN.

Recovering is a perilous activity, which has the potential to lead to recovery but also contains the danger of relapse and failure. To negotiate it requires that individuals do not just become better in the medical sense of the term but also understand themselves more fully. By tolerating the complexity and uncertainties of life without AN, individuals can be transformed by the experience of recovering and develop a greater understanding of themselves. In this way, they acquire increased knowledge of themselves and their capabilities through their own hard work. I will now cover the findings in more detail by outlining each category and its contents and highlighting how they link with one another. I will also engage with the literature in a discussion of the findings to examine both supporting and critical aspects of the emerging theory.

Detailed findings and discussion

Deciding to recover

Any individual with any illness has insight into and knowledge of their experience denied to anyone else and this holds true for AN. Individuals with AN when discussing their illness do so from the privileged position of the insider also known as the emic perspective. Whilst the perspective of those without AN described as the outsider, is known as the etic perspective. These perspectives contribute substantially to the different

positions adopted in relation to both the AN and recovery from it. The individual with AN when viewed from the etic perspective appears as someone who is ill with a mental disorder and in need of help to get well. The individual is often emaciated, physically compromised and in conflict with those closest to them about the need for intervention. Yet as discussed in the introduction they often appear doggedly committed to the AN despite this. As such, this perspective raises difficulties for the individual when it comes to recovery because if they are not concerned by the situation then why change. Participants in this study acknowledged just such an absence of desire to recover but it did not exist in a vacuum. Instead they also had concerns about the AN's impact on their physical and psychological state and their future. What emerges from their accounts is that an active process takes place at the start of their recovering in which the individual reviews their situation and concludes that recovery is necessary. If this does not happen then they will remain ill with the AN. As this participant describes it;

I guess it's really wanting to [long pause] get well, be made stronger.

(P348)

So the first step in recovery is that the individual with AN has to engage in '*Deciding to recover*' and this is the label of the first major construct which emerged from the participants' accounts. Table 3.2 summarises the contents of this major construct. I will take each category in turn to illustrate how they fit into the process of recovering.

Table 3.2: Categories of *deciding to recover*

Major Construct	Categories
Deciding to recover	Recognising the limitations of AN Acknowledging the benefits of AN to them Wanting to be more Fears about recovery Making it personal

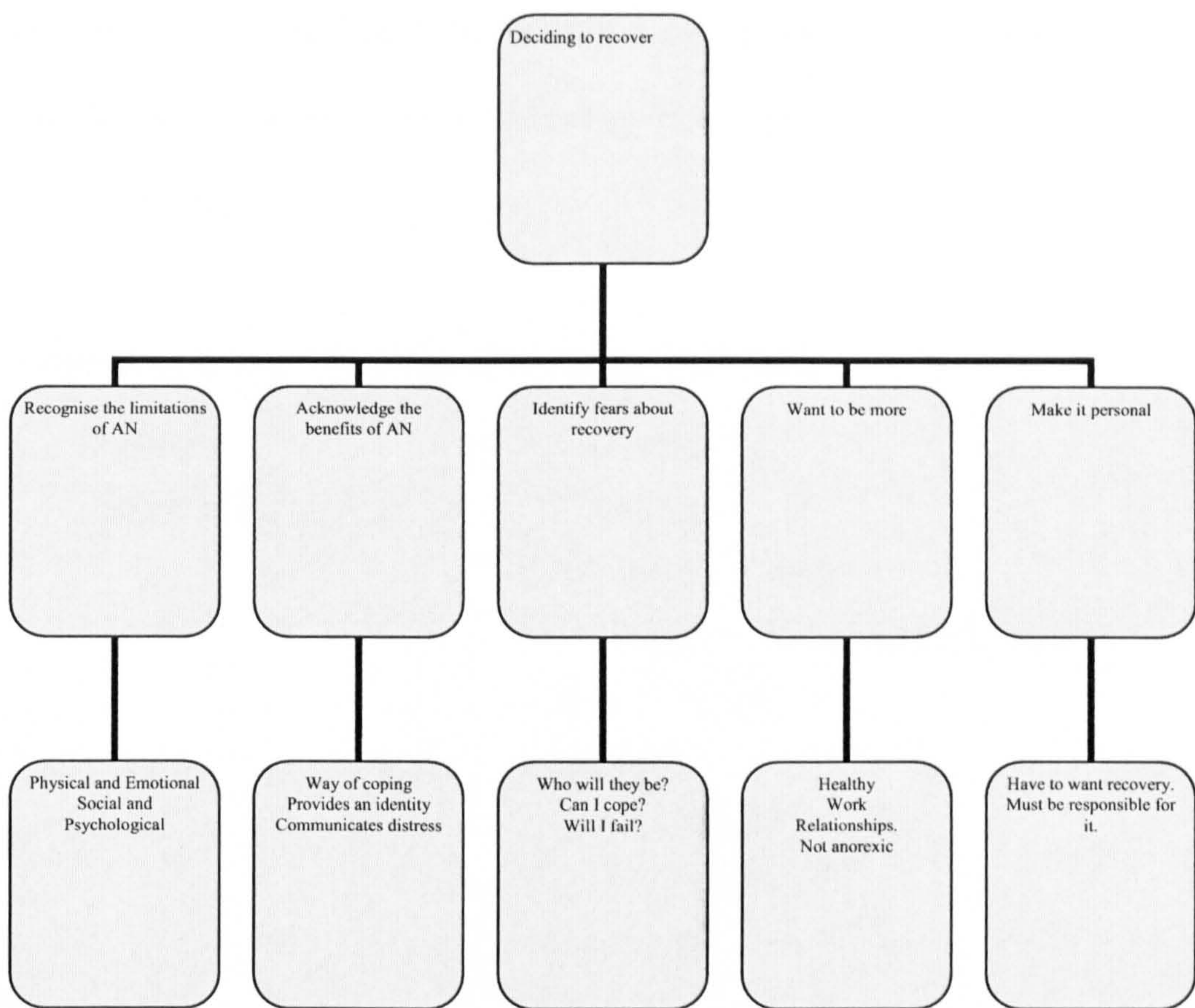
The participants emphasised that without this desire they would not even begin to recover. The participants *decided to recover* when the individual reflected on the ways in which the AN impacted on their lives. This often began when the individual became more aware of the destructive aspects of the disorder, which was part of coming to *recognise the limitations of AN* on their lives. However, this was not sufficient to reach a decision to recover and they had to *acknowledge the benefits of AN*. This was important because these ‘benefits’ to the individual provided by the AN undermine the motivation to recover and act as counterweights to the ‘limitations’ imposed by it.

Traditionally, the advantages and disadvantages of AN are considered to be important in recovering, particularly in the literature on motivation to recover (Geller et al. 2001, Serpell et al. 1999). However, what emerged from this study was that the individual needs to consider two other opposing factors. Participants talked of utilising a *wanting to be more*, which contained their aspirations for a life without AN to support their desire to recover. However their *fears about recovery* counterbalance this desire and contributed to the urge to stay ill. Neglecting the benefits of AN

would lead to relapse because the demands of giving the benefits up would overwhelm the individual's commitment to recover. Another consideration is that, in deciding to recover, the individual has to *make it personal*. By doing so, the reasons to recover are personalised to them because doing it for other people would not be enough to sustain recovering in the long term. This is an important consideration given the extended time scales involved in the process (Strober 1997).

I have deliberately chosen to use the present tense of the verb 'to decide' when naming this category because I did not want to lose the sense of action that participants conveyed. This action stems from both their description of the ongoing nature of their decision-making about recovery (I will return to this later in the chapter) and how the different aspects of the process interacted with and influenced each other. Figure 3.1 below conveys how each of the categories contributes to the overall decision-making. It also outlines just what is involved in each of the separate activities of deciding. Although dealing with each separately for the purpose of clarity in the text, it is essential to be mindful that they all interact with each other, leading to changes in how they are experienced by the individual. They are all mixed in the cauldron of the individual producing different and unique responses to the circumstances encountered by the individual. These responses, in turn, can contribute to recovering or undermine it, depending on their context, and I will demonstrate this within this chapter.

Figure 3.1: Diagrammatic representation of categories contained in the *deciding to recover*



Recognising the limitations of AN

I think you start to recognise that there is a problem. The hardest thing is recognising there is a problem in the first place and then knowing the right people to go to ask for help.
(P345)

Although participants gave differing accounts of the beginning of their recovery, often being uncertain as to when it began, they were clear that

the decision to recover included recognising how AN negatively affected their lives. They did this as part of motivating themselves to recover because recognition of the damage done supported their desire to change. In Table 3.3, I have listed the main sub-categories of this category and, in the following pages; I give examples of the participants' descriptions in their own words.

Table 3.3: Sub-categories of *limitations of AN*.

Category	Sub-categories
Limitations of AN	No energy Poor concentration Preoccupied with weight and shape Loss of friends Isolation Loss of potential Loss of control Low mood Cold Physical discomfort on sitting/lying Conflict with close others

This category incorporates the physical and psychological deterioration that accompanies the characteristic behaviours of a person with AN. These are the result of their driven efforts to reduce their calorie intake and weight, as well as those of excessive exercise or purging behaviours. Physical frailty, obsession with food, social isolation and loss of opportunities are all a part of this. Participants can experience AN as a

negative aspect of their lives as well as in the lives of others. Here are a few examples:

Physical

Um...physically I suppose not aching, feeling cold, the dizziness and the physical cold that go with eating problems. (P348)

Emotional

Yes I think so because when you are ill you have no emotions. You just kind of...a bag of nothing really. It was. Um... [pause] it was...my life was full of depression, blackness and I couldn't see a way out. (P341)

Social

Yes it does because as a person you change because you haven't got the energy to do anything. You don't go out with your friends as much because they want to go out for meals and that and you can't bring yourself to do it really because it's an awkward situation. Um...you're moody and lose friends. It changes you totally as a person. A lot of people just look at you and think ...eugggh! (P346)

Psychological

And you don't know what recovery means. When you're really ill you don't even think about recovery to start with. You're just going through

your day-to-day pattern. You don't think of recovery at all. When you're actually...it doesn't appeal to you at all. (P344)

Impact on others

It's been really hard for them to see how ill I was and then they've fought all the way with me to try and get the weight back on. Umm...I hate myself having done that to them and I really...they didn't deserve it at all. (P345)

Ancel Keys (1946), in a classic study looking at the impact of starvation on human beings, reported findings many of which are paralleled in the experience of those with AN. All of these impacts, whether on the individual or others, are experienced as aversive to the individual. Other authors have also written about the unpleasant consequences of AN, both in the professional literature, books and journals (Zipfel et al. 2003, Pomery & Mitchell 2001) and in accounts of those who have recovered from the disorder (Pettit 2003, Hornbacher 1999). Serpell and colleagues (1999), in a study looking at the view of AN held by those with the disorder, asked their participants to compose letters to their illness as a friend or a foe. On reviewing the themes that emerged from the letters, they identified a group of themes which they labelled the 'anti-themes'. These included impacts on the person's health, their mood, impact on others and the waste of life associated with having the disorder. They also pointed out that these themes were important in recovering because they could be engaged with to help the individual increase their motivation to change their behaviours.

They concluded that these themes were experienced as motivators towards recovering because the individual is likely to want to get rid of these effects.

A study by Cockell and colleagues looking at the application of a 'decisional balance' measure in the field of eating disorders provides further support to this category (Cockell et al. 2002). In the study, they asked 246 women to complete a questionnaire with 60 items. Following analysis, they found a three-factor solution that they labelled 'Burdens, Benefits and Functional Avoidance'. The first of these, 'Burdens', contains many of the negative aspects of the disorder which the authors link to the anti-themes of the Serpell (1999) study and conclude that they are important to recovery because the individual sees their situation as being in need of change. The similarity of these findings to those that emerged from this study is reassuring in that they add to the validity of this study's findings. This in turn supports this group of effects as a robust finding for those with AN at least in the settings for these studies that of specialist eating disorders services. These studies are important for other sub-themes of *recognising the limitations of AN* and I will return to them later in this chapter.

It is important to note that the consequences discussed above are usually the most observable to those without AN, which can give rise to a different set of circumstances. Sometimes the decision to seek out and even to start recovering was prompted by those closest to the individual. This

situation usually occurred when the individual was very unwell with AN and did not act to remedy the situation. As this participant states, she was not going to cooperate because she was not in the *recovery stage*:

It was obvious I wasn't going to cooperate too much – I wasn't in recovery stage. My mum took me down because she knew I wasn't right. (P346)

Participants stated that this was either because they did not think anything was wrong with them, as above, or they were so preoccupied with the demands of AN that there was no time to consider recovery.

It was like kind of something I was really in control of and it was something I really focussed on – it was my main mission in life just to keep losing weight. (P347)

However if they were to recover they had to recognise that the AN was limiting what they could do. In the next quote, the individual recognises that something that had originally been experienced as a means of controlling things no longer functioned. Instead, she now felt unable to control it and the consequences were that she was admitted to hospital because she could no longer turn it around on her own.

When I was low weight – the choice wasn't mine – I was out of control and I couldn't control it. Though it started as my way of

controlling it, it became out of control. Then I couldn't pull it back on my own then. I needed to go as an in-patient. I kept telling myself I was going to pull this up – I'm going to eat this, eat that – but it never happened. I needed the help then but it was down to me. Whether I chose to get better or not. (P342)

These resemble the circumstances in which individuals with AN are not considering any change to their behaviour and so others intervene to prevent what they see as further harm. Participants suggested that this was sometimes appropriate because they were unable to act for themselves due to the power of AN and the effects of starvation. However, this could not remain the basis for full recovery and the responsibility had to be handed back to the individual as soon as practicable or they were likely to begin to resist treatment that could appear imposed. I will return to this later in the study but first I shall discuss the second category, that of *wanting to be more*.

Wanting to be more

I just knew I wasn't meant to be this way. I know that I had been so out of it for so long that I know that there had to be more to my life than where I was at and I was just determined to be different to be free, to be free from being so unhappy for so long. I know I had to change because it was so miserable I sort of know I had to do something to get out of it. (P351)

This category contains what participants saw as events or effects that either immediately reinforce recovering or are anticipated as being longer-term positive outcomes of the process. They contain the individual's hopes for the future and their desire to be different from how they are now. As the participant above notes, she just knew that she '*wasn't meant to be this way*'. Table 3.4 below outlines this category and the sub categories that emerged from it.

Table 3.4: *Wanting to be more* category and the sub categories

Category	Sub-categories
Wanting to be more	Improved physical state Stop wasting their lives Improved mood Impact of AN on others

When deliberating about recovering, the most obvious area that will benefit from any change in behaviour is the individual's physical state. Participants cited not feeling cold, having more energy, the return of the chance to have children, improvements in mood and a return to 'normal' life as all contributing to decision-making about recovery. Whatever the benefits may be, participants stressed that they have to be personally meaningful to the individual if they are to have any influence. This is because these influences provide the reasons why the individuals with AN will continue recovering; without them it will not happen. The first sub-category relates to the improvement in physical condition, which was the result of the negative effects listed in the sub category of deciding to recover *limitations of AN*:

Once the first few pounds go on you start to feel yes I can do this – and the more weight you put on...like now I have so much more energy, I generally feel warmer. Like before even with the heating on I'd always be cold and have big jumpers on. Now I don't feel like that at all and can walk around in T-shirts and feel fine. You generally feel more comfortable and it's those little things that make you realise that it is actually worth putting the weight on. (P345)

Therefore, in these circumstances, individuals feel less restricted by their physical condition and generally more 'comfortable'. In turn, this positive outcome helps them to continue to recover because it reassures them that recovering is worth the effort they are putting in. The synergy between aspects of the recovering process is obvious in this quote with the linked but different consequences that arise. This is important to the process because it increases the rewards to the individual. A further example would be when the individual begins to improve their physical state, which has the effect of reducing the anxiety of those closest to them. This is rewarding to the individual because they feel less guilty about the impact of their disorder on others.

This participant reveals how thinking about how the physical changes brought about by AN made it impossible for her to have children, something that was important to her and acted as an impetus to recovering:

Also, I always used to think of the bad points like if I carry on...The main thing was having kids because all my periods and everything stopped. That was the main thing – when you think about that. (P346)

The very personal nature of this motivation needs to be acknowledged because it may not apply to others but, its personal nature, reinforces the important role such motivations play in recovery for each individual.

Within this category, participants reported an increasing awareness that they were in many ways ‘*wasting their lives*’ and missing out on things that their friends were engaged in whilst they were ill with AN:

I guess I don't want to go on missing out on opportunities because that makes you feel like you want to change...being with friends and seeing what they do and seeing what I'm doing – wanting to do what they do and being round friends that also makes you want to recover. Thinking of all the time I've wasted being ill which is most important also helped. (P348)

This awareness has to be contrasted with the denial of illness that is regularly reported as part of the presentation of AN. They are mutually exclusive in that individuals cannot deny any problems when they are aware of how they are wasting their lives. Therefore, the presence of this awareness is an indicator that the individual is more likely to change than

those who deny the illness. This participant is anticipating that the recovering process will be worthwhile because it will make her a stronger person and she will know how she deals with things. She believes that it will all be worth it in the end:

And, I mean, whatever happens at the end of this, I will come out a stronger person. I will know how I react to things and how I deal with certain things. (P350)

This description of the increase in self-knowledge in the participants because of the recovering process occurs in other categories of the study such as *doing the necessary tasks* and *taking on new roles*. The suggestion is that the recovery process changes the individual and this change enables further recovery to take place. If individuals do not acquire a greater level of self-awareness then they are unlikely to progress their recovery.

Another important subcategory, *The impact of AN on others*, shares common ground with another subcategory; that of the role others have to play in the recovering process. At this point, just one example to illustrate its role in the consideration of recovery is needed. This participant acknowledges how the fact that she can function better on a day-to-day basis and is able to look after her children is a motivator for her and reminds her that recovering is worthwhile:

Now I can function on a day-to-day level like most normal people and my worries about food I can be conscious with them rather than wanting to be unconscious without them. So the fact that I'm out and about and looking after my kids and for example, I'm taking them to the cinema this afternoon. (P347)

Individuals with AN experience these conditions as promoting their recovering. The combination of the immediate and anticipated benefits of recovering *makes you feel like you want to change (P348).*

In the studies by Serpell (1999) and Cockell (2002) cited earlier, the authors developed two very similar concepts – the 'anti-themes' and 'burdens' – to describe their participants' negative feelings about their illness. Some of the themes that I allocate to this category are included in their concepts and I need to explain why I have this extra category. The studies quoted above focussed only on the participants' views of AN and not on recovering from it. The Serpell study asked participants to write letters to AN as friend or foe whilst the Cockell study asked them to complete a questionnaire on the costs and benefits of AN. Therefore, I believe the authors limited the participants' scope of response to commenting solely on AN, a danger associated with questionnaire studies. In my research participants were encouraged to speak about the process of recovery from AN and were not limited to what they thought about or how they constructed AN. Data collection was via an interview with only limited prompts to orientate the individual to the topic. The fact that themes

found in the earlier studies also emerged in this study supports the findings.

However, participants in this study spoke about 'recovering' as having an importance separate from the AN, and that the anticipated benefits and, more surprisingly, anticipated costs contributed to their decision making about whether or not to stay ill. A risk of treating AN and recovery from it as one and the same is that recovery is limited to the absence of symptoms of AN and excludes the other markers that the participants in this study indicated were necessary for recovery. One consequence of this neglect of the true nature of the recovering process is that it leads to an underestimation of what is required to recover, which is a theme I will return to elsewhere in this study. Therefore, in keeping with the methodology and in grounding the theory in the participants' accounts, I include not one but two subcategories to do with recovering: the benefits and risks associated with it.

Having described so clearly the negatives of having AN and the benefits of recovering, participants also conveyed their belief that these were not sufficient by themselves to capture the complexity of recovering from AN. In the introduction to this thesis I highlighted that individuals with AN are often described as reluctant patients (Palmer & Treasure 1999) and appear less concerned than others about their situation. I have witnessed this presentation during my clinical practice and it contributed to my decision to study recovery from AN. The existence of this characteristic means that

those without AN struggle to comprehend why individuals do not change their condition when it appears the obvious thing to do. The participants described a series of conditions that had the effect of reinforcing their AN, either directly through the benefits it provided or indirectly in that it avoided dealing with the work of recovering. Two other categories I have labelled *Acknowledge the benefits of AN* to them and *fears about recovery*.

Acknowledging the benefits of AN

Often, participants were aware of wanting to recover for a time before they began to undertake recovering activities. They explained that this was due not just to the negative effects of AN on their physical and psychological well-being but also because of the benefits the AN brought to them. Others explained that this was because they did not think that anything was wrong with them or they were so preoccupied with the demands of AN that there was no time to consider it. The denial of concern is a characteristic of AN that was reported in the literature and was discussed in the introduction as being relevant to the value of the responses of those with AN in research studies (Vitousek et al. 1991). Benefits of a mental illness are not a common finding in research studies. However, it is the case in this study and, as will be shown later in this section, has been reported in the literature. Table 3.5 outlines the benefits participants ascribed to AN, and I will describe these in detail because of their role in the process of recovering from the participants' perspective.

Table 3.5: Subcategories of category *acknowledging the benefits of AN*

Category	Subcategories
Acknowledge the benefits of AN to them	Boost to self esteem A sense of identity A way of coping with difficult issues Communicating with others Excused from other’s expectations

There was a part of me that was proud I could push myself that far, have that amount of self-discipline. (P350)

Here the participant speaks of the pride she felt in being able to push herself so hard and to demonstrate self-discipline. For her, this led to a sense of achievement and a boost to her self-esteem through the recognition of aspects of herself of which she could feel proud. Vitousek & Manke (1994), in their paper on personality variables in eating disorders, suggested that a deficit in self-esteem is a central component in the causation of AN and that the sense of achievement experienced by those with AN when they lose weight is a significant factor in maintaining the illness. Determination and self-discipline are also characteristics that draw admiration from others. Slade (1982), in a functional analysis of eating disorders, suggested that this demonstration of discipline is designed to show not only him or herself, but also others that they have worth. For the individual who has low self-esteem, the admiration of others for their display of self-control and their own endorsement of the ascetic ideals of

denial of need and self-discipline are likely to be powerful rewards of the illness. Without addressing this, recovery will not happen, and as I shall show in the categories *taking on new roles* and *dealing with underlying issues*, participants indicated that this was necessary.

Slade's (1982) overall formulation of AN was that it was 'an attempted adaptive strategy (which has functional value to the individual) given the major setting conditions of the individual's current life situation' (p.167). Therefore, the AN can be seen to function as a way of dealing with other aspects of the individuals' life. Participants in this study also reported this as a feature of their AN. The following quote captures the sense of AN as a coping mechanism:

I think it served, it served a lot of functions for me but I have only been able to see that in retrospect, in getting better because I can see that I have used it as a control mechanism but also as a way to cope.
(P349)

The next quote from a participant adds to the concept by including an outline of what she was coping with – a personal sense of worthlessness:

Then it was just a whole cobweb of different things that made me spiral into this feeling of just being worthless therefore why should I be here and then guilt about being here and guilt about eating. If there was one thing I could keep control over, even though I couldn't

control what I was thinking about myself, I could control what I was putting into my body. (P347)

Both of these participants introduces the concept of 'control' – I have allocated a separate category to this because it emerges often in the participants' accounts as they discuss various aspects and stages of the recovering process so I will not address it further here. In the Cockell study (2002) looking at the use of decisional balance with eating disorders, the authors were surprised to find that, instead of the standard two factor solution found in other populations studied, a third factor which they labelled 'Functional avoidance' emerged. This factor contained the ways in which the individual with AN uses the AN to avoid some other activity or event that they either knew would be or anticipated would be unpleasant and difficult.

Individual participants spoke of how the AN served as a means of communicating with others in a number of different ways:

So then when I was ill I was at the centre of it and I suppose people were looking at me and thinking 'oh you poor thing'. (P342)

Her appearance when she was '*at the centre of it*' informed people of her condition and drew sympathy from others as a result. The next quote is more specific about communicating with others whilst it also highlights how she is pleased by her thinness but knows others see it as a problem:

Before, if I went out anywhere and people were looking at me, although I was thin at the time I was pleased to be so thin. I knew people were looking at me thinking 'my God, look how skinny she is – she's obviously got a problem'. (P346)

This next quote highlights another aspect of AN as a means of communicating with others. The individual's condition not only elicits sympathy and care but also means they are protected from the expectations of others who might make demands on them, which they could not meet. They were therefore excused the responsibilities associated with being an adult, of being there for others, because they were ill:

...and you almost didn't have to be the person for other people because you weren't well enough to and I suppose it wasn't expected of me. (P342)

Gale et al. (2006), in their study aimed at developing a questionnaire to measure the pros and cons of eating disorders, looked at factors in both AN and Bulimia Nervosa. They identified a factor they labelled 'Communication: emotions and distress' which closely resembles the sub theme of communicating with others described above. Their participants endorsed statements such as 'my AN is a cry for help' or 'I use my AN to communicate my distress/unhappiness to others'. Other researchers have

also reported a similar function for AN (Cockell 2003, Serpell 1999). Participants were clear that to recover they had to develop new and healthier ways of communicating with others. This quote provides a link between the theme of avoiding responsibilities to others and another theme which emerged that of AN providing an identity to the individual. It also eloquently conveys the fear the individual experiences and the doubts she has about who she will be or how she will be perceived by others.

People know me as Sara [all names have been changed] the anorexic. Because I've been like it since I was quite young so this is how they know me. If I didn't have it what would I be? Would I be just Sara – I wouldn't be Sara the anorexic, I'd just be Sara and people would expect me to do normal things. (P351)

The individual knows herself and is known by others as an 'anorexic' and is concerned that she would not know how to be any other way or how she would cope with the expectations of others if she were not. The AN provided a way of being in the world and of being seen by others that had distinct advantages for the individual. She also notes that the length of time she has had the illness contributes to the strength of her 'anorexic' identity, suggesting that the longer one has AN the harder it may be to recover. Such a position is supported in the outcome literature where there is a clear link between duration of illness and less good outcome (Steinhausen 2002, Pike 1998, Herzog et al. 1997, Ratnasuriya et al. 1991). Hilde Bruch (1982, 1981, 1978) suggested that AN is caused by impairments in identity

formation, attributable to particular parenting styles which limit the opportunities for autonomous functioning. She also suggested that the choice of body weight as a means to self-determination is made because it is controllable and is both personally and culturally important. Therefore, she suggests the AN comes to represent an attempt to develop a sense of self, linked to exercising power and control in a setting of powerlessness. These descriptions encompass the ways in which AN can come to serve a particular and valued function for the individual and this view was endorsed by the participants of the study. When this happens, recovery becomes more difficult.

The adoption of the AN identity is marked by certain characteristic ways of behaving if it is to deliver on its promise of power and control. I mentioned the self-denial and discipline associated with it earlier and the next quote conveys some other characteristics noted by this participant, who also covers what this means in terms of recovery:

It's stayed with me through thick and thin...That's the thing, recovering means getting rid of it – losing a friend and this is so scary because I view it as a friend and if I was to recover I'd be losing like my best friend so who would I have? (P344)

The participant is remarking on how helpful she found the dependable and consistent presence of the AN in her life. In a way, it is a predictable and reassuring, if destructive, presence in the person's life. Recovery would be

scary because it would mean her giving up this AN and then what would she do? Way (1993) states that 'When anorexia nervosa becomes intrinsically tied to a woman's identity, she clings to it desperately – because it's all she feels she has' (p.69). She goes on to suggest that this 'is *precisely* why anorexia nervosa is so difficult to overcome' (p.69, emphasis in the original). The recognition that recovery cannot happen without relinquishing the AN, coupled with the fear of giving it up, also speaks to the ambivalence that the individual with AN often has towards recovering from it. I will return to this later but first I will look at some other aspects of the identity associated with having AN in the literature.

In describing a maintenance model for AN, Schmidt & Treasure (2006) suggest that, amongst other things, the personality traits, particularly perfectionism and obsessive compulsive traits, of those who have AN are both risk factors and maintaining factors. They suggest that individuals with such traits 'value perfection and fear making mistakes' and that 'being rigidly rule bound, striving for perfection' (p.349) can facilitate behaviours associated with AN, such as restricting dietary intake. They suggest that a wish for simplicity and a focus on detail may make the AN behaviours 'satisfying' to the individual. The AN is overlaid on their personality and becomes their way of dealing with the world. It also becomes the way in which others see them. This simplifies their life, and the predictability and simplicity is attractive to them. As recovery means relinquishing this simplicity because life is unpredictable and complex, such a theory would predict that recovery would be perceived as difficult. Participants in this

study said as much and this is evidence that they are not just getting over AN but battling some of their personality traits as well. Although the authors of the above study show support for the presence of the traits in those with AN, they note that there is currently no evidence that they affect outcome or that treatment interventions aimed at these traits have any impact. However, participants in this study did convey a concern about the unpredictability of life without AN, which contributed to the uncertainty in the recovering process. This was factored into their ongoing decisions about continuing to recover.

Other authors employing qualitative methodologies to explore this in a different way imply other factors in the maintenance of the AN identity. Hepworth (1994), in her book on the social construction of AN, and Hardin (2003a), in her article on recovery from AN, both discuss the dangers inherent in labelling someone as 'anorexic'. They suggest it can set the parameters of the individuals' existence and therefore contribute to the maintenance of the problem. Participants in this study suggested that they were, in a sense, staying true to their 'anorexic' identity and that acting outside of it would be wrong. Malson and her colleagues (2004) employed a discourse analysis methodology to examine how individuals with AN described their treatment experiences. They also focussed on the construction of the 'eating disordered patient' by individuals with AN. The authors found that both individuals with AN and healthcare workers were likely to construct the individual as '100% anorexic' and that this had implications for how both groups acted and interacted. For the individual

with AN who constructs him or herself in this way one consequence is a belief that they must behave in keeping with the persona associated with AN. If they engage in behaviours, which are not in keeping with this, they will experience a sense of guilt and the urge to return to the AN. If this sense of guilt is too great for the individual to manage then recovery is experienced as unpleasant and may be abandoned.

However, Malson et al. (2004) also reported that the degree to which an individual felt positive about remaining with their eating disorder was positively correlated with the pros and negatively correlated with the cons. They found that the opposite was true for those who felt negatively about staying with their disorder. They noted that 'it was the degree to which the individuals endorsed pro themes, rather than cons, that was most consistently correlated with their attitude towards the illness' (p.402). This suggests that it is the perception of the advantages that most influences the individuals' view of their illness and whether or not they will want to recover from it. The authors assert that the 'positive aspects' of AN may explain the 'poor motivation to change and contribute to the maintenance of the disorder' (p.394).

Overall, the literature is clear that the perceived advantages of AN are significant and need to be addressed if the individual is to recover, something with which the participants in this study concurred. Therefore without addressing the positive aspects of the AN as perceived by the individual no recovery is likely to take place. This is because the individuals

remain committed to the AN as a way of coping, a solution or providing them with an identity which they otherwise would not have. That AN has benefits for the individual also has implications for any treatment proposed for AN. It is likely that any treatment will be perceived as a threat to identity and therefore they will resist it. I will return to this within the sub category of *getting support from others* later in the thesis.

Alongside articulating the benefits of AN, participants in this study suggested that, by relinquishing the benefits of AN, they are likely to be anxious and fearful of what will happen to them. How will they cope without the AN? For them, recovering is more than giving up the benefits of AN – it is also the necessity of dealing with the work of recovering. Thus, to recover individuals with AN have to tolerate the distress that inevitably accompanies changing how they manage their lives and find alternative ways to address these needs. It is in the scale and nature of this task that the difficulty of the recovering process is partially captured, as will be shown in the next section *managing their fears about recovery*.

Managing their fears about recovery

Recovery can be quite lonely because you haven't got that kind of...If it's a cry for help like, 'hey look at me, I'm struggling,' well you haven't got a physical way of showing it. (P349)

This quote is linked to a previous sub theme 'communicating with others' and introduces some of the consequences of no longer relying on AN to

communicate distress. Relinquishing this benefit can lead to individuals feeling lonely and without a means of letting others know how they feel so they have to find an alternative means of fulfilling this need.

It is not surprising given the previous section that participants might speak of recovering as having negative aspects. Giving up the benefits listed above would constitute a significant task (Halmi et al. 2005) and would require significant effort from the individual. What is surprising is that this is not regularly captured in the literature. There is a recognition in the literature that it is difficult to recover from AN and that it is a long process requiring substantial effort on the part of the individual (Cockell et al. 2004, Finfgeld 2002, Herzog et al. 1997, Hall 1993, Way 1993, Hsu et al. 1992, Beresin et al. 1989). This is usually found in a small number of sentences which describe the sentiment at the beginning of the study. There is no attempt to provide descriptions as to why this recovering is so difficult. The literature is rightly criticised in my view because it confines itself to listing prognostic factors or activities that were beneficial to recovering whilst providing little as to the experiential aspects of recovering (Jarman & Walsh 1999, Pike 1998). The possible reasons for this, as I have discussed in the introduction, include a focus on the more measurable indicators of outcome and on the AN itself, rather than on recovering from it from the perspective of the individual with the disorder. I concluded in the introduction that this potentially limits our understanding of what is required to recover and neglects a valuable source of important data on this topic.

In keeping with my methodology, I initially refrained from reading parts of the literature that may have prejudiced the data collection with concepts of recovery other than the ones I carried myself. However, as the study progressed and I engaged with the literature I identified a number of studies that focussed on the individual with AN's perspective on recovery. (Couturier & Lock 2006, Lamoureux & Bittorff 2005, Noordenbos & Seubring 2006, Jones et al. 2005, Tan et al. 2003, Hardin 2003a, Tozzi et al. 2003, Button & Warren 2001, Hsu et al. 1992, Beresin et al. 1989). The fact that the majority of these articles were published in recent years is a welcome confirmation of the increasing frequency with which the views of those with experience of the illness are being sought. However, even in this literature, there is a focus on the factors that aided recovery or contributed to relapse, as well as analysis of AN as a disorder and how it contributed to both these outcomes. There is limited space allocated to the experience of recovering itself, aside from it being hard and that there are things individuals need to do to recover. The risk, as I see it, is that this leads to an underestimation of what is actually required to recover. The consequences of this are significant for the individual with AN and those trying to help.

In this study, all the participants, those who had completed the recovering process and those who were still undergoing it, spoke of how uncomfortable and difficult their experience of it was. This is important because, as mentioned in the methodology, I did not exclude participants based on their clinical status. I did not do so for a number of reasons but

mainly because I was interested in recovering from AN from the perspective of the individual with AN. Including those with the disorder as well as those who had recovered from it allowed for a greater range of data on the process to be collected. Including their view would also help to counter the charge levied at the literature in the introduction that the interests of the professionals and academic researchers who carry out the research drive the definitions of recovery.

The aspects experienced as aversive consisted of both giving up the benefits of AN and what was required to live life without it, such as managing their emotional life. For example, individuals would not only have to relinquish the sense of achievement associated with losing weight but would also have to tolerate weight gain. These are two completely different aspects to manage, as illustrated by these two quotes:

When the weight does start to go on – to start with, it is really scary and you kind of lose control of something that you have had tight control of all the time and you feel frightened that you're going to lose control and not stop putting weight on. (P344)

I guess so. I could never use gaining weight as a measure of achievement. It has always felt like a failure, like giving in. (P349)

The first quote relates to fears that when they start to recover and gain some weight they will no longer be able to control their eating and will just

keep gaining weight. This demonstrates an erroneous belief that exists within AN that eating will mean continuous weight gain. This is one of a series of thoughts associated with AN that will have to be disproved for recovery to continue. Unfortunately, this occurs 'in vivo', so to speak, with the individual having to begin to eat to find out what will happen. Participants stated that trusting the information they received about this was important, as was who gave them that information. The second quote relates more to the experience of weight gain as a failure, as somehow giving in to something. This is in contrast to the boost to their self-esteem associated with weight loss. The importance of this for recovering is that they experience these events negatively, and as such, they make the process of recovering unpleasant to the individual. If they are not committed to the process then these experiences are likely to undermine it. Participants also wanted to convey the sense that the loss of self-esteem from weight gain and the feeling of being out of control could combine to undermine this commitment further. The drop in self-esteem associated with giving up the maintenance of a low weight undermines the individuals' belief in their ability to cope with the loss of control experienced when restoring weight. The result is less confidence in dealing with the demands of recovering and a greater risk of relapse.

Recovering from AN is difficult and demanding and has some unique challenges that are not present in other disorders. I will return to having to eat within the *necessary tasks* category and will restrict myself here to looking at the peculiarity of food in contrast to other disorders where the

intake of substances leads to problems, such alcohol and drugs. Food plays a central role in our day-to-day lives. This role makes it unavoidable, so the option available to those with alcohol or drug problems of 'doing without' is not available to those with AN. This has a major impact on the experience of recovery because individuals with AN are compelled to come face to face with food as illustrated by this participant:

The problem is I think that if you were an alcoholic, for example, fair enough you are put into situations where alcohol is available but you can distance yourself from these potentially whereas. With anorexia, you have to face food every day, interact with food every day...It is a constant thing you have to face. Like I said, you have to be aware of it all the time. I thought about food a lot in my anorexia but actually, I am actually going to think about it more in recovery. Just the thought of it having such a domineering part in my life is scary. (P351)

Not only is food a constant concern during the AN but, during recovery, it becomes more important as individuals rearrange their relationship with it. Participants point out that social activity often takes place at events and in settings that include food as an integral part of the activity. As participants explained, this means that exposure to such situations would be a significant part of their recovering and would be difficult to manage or control.

This example demonstrates how the categories, which emerged in the study, interact with each other and contribute to the sense of dynamism conveyed by participants about recovering. Here, improvement in the area of food behaviours is likely to increase the occurrence of social activities, both of which participants perceived as positive in the context of recovering. Equally, limited improvement in food behaviour will also limit social opportunities, which will compound the individual's isolation, all of which are perceived as negative for recovering. This interrelatedness between aspects of the process and their capacity to influence one another is important for the ongoing commitment of the individual to recover. Participants emphasised how this interaction was a constant presence in their lives, prompting consideration and reconsideration of what to do next in the context of their recovery. They convey the effort and commitment needed to maintain their recovery, particularly given the comments about the importance of returning to what they describe as a 'normal life'. Both of these observations are relevant to the basic social process, developing a more complex identity, which is described later.

Another aversive aspect of recovering is the physiological reaction of human beings when restarting eating. Keys (1946) found that individuals who have restricted their food intake undergo a number of responses, which are uncomfortable. Individuals report feeling bloated after small amounts of food, stomach pain due the stomach lining stretching to accommodate the amount of food consumed and, occasionally, feelings of nausea. Szmukler et al. (1995) reported similar findings and attributed

them to the delayed emptying of the stomach, while Schmidt & Treasure (2006) note that the 'prospect of having to eat becomes a threat associated with these aversive consequences' (p.347). For participants, the impact of such experiences was to make them regard eating as unpleasant and to begin restricting their food intake or purging behaviours in order to remove the unpleasantness. However, participants' comments were not limited to the physical consequences of restarting eating; they also spoke of the cognitive and emotional consequences. Eating anything outside of the limited range of foods they allowed themselves was seen as a failure and led to negative emotions. A significant one, which arose in many different contexts, was guilt.

Guilt

Guilt; remorse or self-reproach caused by feeling that one is responsible for a wrong or offence.

(Collins Concise English Dictionary 1982)

This definition of guilt conveys what participants experienced and struggled with in the recovering process. Participants found this to be a prominent part of their recovering and a difficult emotion to deal with. Guilt could also arise in the context of two apparently opposing sets of circumstances, as illustrated in the following quote:

Because I was like it for quite a while there is still something quite deeply ingrained that kicks its head up now and again and if I eat less

in a day I feel kind of like I have achieved something, which isn't right at this stage as I'm still trying to put weight on. I know it's not right and when I do get those feelings I do kind of feel a bit guilty about it. Before I felt guilty if I ate too much whereas now if I eat too little I feel guilty about that. (P345)

For this participant, the guilt arises when she perceives she is breaking both the rules of AN and the rules of recovering as she has laid them out. Participants spoke of how the guilt arose in a number of contexts, such as in spending time focussing on him or herself. The AN allowed them to become more self-absorbed and more focussed on their own needs. However, this is false in that it was only a limited set of their needs being addressed and was achieved only through becoming more isolated from others. Taking time for oneself is described and experienced as being selfish by participants and, as such, is a negative for them. Cockell et al. (2002) report similar findings in their factor analysis study, particularly in the factor they describe as the 'burdens' of AN.

For participants in this study, the guilt also contributes to them becoming more isolated from other people, as they seek to avoid not meeting the needs of others. Connors (1996) suggests that one of the possible vulnerabilities to developing AN is the individual's temperament and personality characteristics and that, because of their concern about how others see them, they are overly eager to please and compliant. In order to recover, they recognise that they need to strike a balance between

spending time focussed on their needs whilst increasing time spent with other people. They have to address the feelings of guilt and run the risk of others thinking they are ignoring them. When the isolation is due to a low level of self-esteem, to overcome it they have to accept that they are worthy of their own and other people's time and attention. In a sense, they have to resolve the dilemma of time for self as opposed to time with others. All of these tasks bring with them an exposure to situations and emotions that the individual participants describe as difficult and demanding. If they are not prepared for them or are unsure about their reasons for recovering, the risk of relapse will increase. However, if they have altered the beliefs they hold about food and see recovering as something they want, then they are likely to continue their recovering journey as indicated here:

To recover you would have to have less of the guilty thoughts and that food is a bad thing. (P343)

Another aspect of the 'guilt' that emerged from the study was related to how the AN impacts on others. The process of recovering includes the need for the individual to come to terms with the often-negative impact on friends and family. Not recovering was a way to avoid the guilt they felt about the effect the disorder had on others. Therefore, the dilemma becomes even more complex for the individual. Staying in AN becomes a solution that allows individuals to focus on themselves. However, the cost is that they withdraw from others which has an impact on those closest to them, causing hurt and difficulty. This in turn leads to guilt for having done

that, but the only way they can prevent it continuing is to embrace the guilt associated with focussing on their own recovery, thereby running the risk of creating further guilt . Such a scenario could easily lead to the individual feeling stuck or engaged in an internal struggle as to how best to act. The quote below captures the complexity and challenge of the dilemma. It also acknowledges the power of AN and the need for the individual to address this in recovering, which is a separate section of this chapter.

It's wrong, it just doesn't work [others taking over responsibility for feeding] and it just makes you feel worse about yourself because you feel you're letting them down as well as letting yourself down. At that point, letting yourself down is eating and letting them down is not eating...So there's a real conflict in your head there as well but you don't want to let other people down but by not letting them down you're letting yourself down and it's you you've got to live with not them. (P347)

It is clear from this that the individual is trying to resolve a dilemma and whichever route they take they are likely to encounter negative emotions, which they have to tolerate.

Overall, individuals are faced with many challenges in their deciding to recover. These range from consideration of giving up the perceived benefits of the disorder, finding alternatives to the benefits, dealing with the consequences of acting against the AN identity, addressing the impact of

the disorder on themselves and others, accepting that others cannot really appreciate what is involved in their recovering, as well as eating food and restoring weight. They have also to deal with their fears about the time when they are recovered or if they ever will be.

As I've said before, sometimes I'm sort of frightened of myself because I just like... particularly now I'm getting so much better and putting this weight on but I'm frightened that once I get to a sensible weight that there is still going to be something that's really deeply ingrained that is always going to tell me to cut back a bit and try and maybe lose a pound this week. I am frightened there is always going to be that thing there, which I cannot control necessarily. But it's not so much... I do not know if it is me or like the illness and whether it will ever completely go – I do not know. (P345)

Such a prospect can appear daunting and is compounded by its unpredictable nature, because those who suffer from AN value simplicity and certainty (Vitousek & Ewald 1993). Given this, it is not surprising that participants speak of the battle or struggle they face when engaged in recovering from the disorder.

This is compounded by participants highlighting how the same event can have both positive and negative consequences for them, which as a result, support or undermine recovering. In discussing the above four categories, it is clear that AN and recovery are perceived as both beneficial and aversive. Both those who remained ill and those who recovered described

recovery as aversive. Instead, all the participants acknowledged the capacity of events to have two opposing meanings. Weight restoration means becoming physically healthier as well as having to deal with more anxiety. Having no emotions can be both unpleasant in the sense that you do not feel any positive emotions and pleasant in that you cannot feel any hurt. The significance of this is that starting to recover does not necessarily lead to a smooth continuous journey towards recovery. Instead, individuals are faced with situations and circumstances that they have previously managed with their AN and it remains an option for them to continue to manage them in this way. Participants were clear that it was when they felt overwhelmed by the demands of recovering that it was most difficult to manage. This sense of loss of control contributed to recovering being experienced as perilous.

The presence of such a theme was surprising because I had always considered recovery to be a good thing and that whatever was required was worth it. The reasons for this could lie within the normative perspective into which I had been socialised in my training as a nurse. Looking on recovery as a positive thing could lead to the underreporting of negative experiences of it because they are not part of the dominant view. Alternatively in AN, which has poor outcomes (NICE 2004, Steinhausen 2002), any focus on the difficulties of recovering may be viewed as undermining even this limited response. It could also be considered as reducing hope for a successful resolution of their difficulties. However, not reporting it underestimates what is required to recover and participants in

the study remarked that others often did not appreciate how hard the recovering process was for them. They felt that others were therefore not appreciative of the efforts they put in. Disguising such demands underestimates what the individual can contribute and, as discussed earlier, constructing an individual in a particular way can set the agenda for treatment and the response to it (Malson et al. 2004). Finally, I also believe it maintains a focus on the individual and the AN as the main contributors to any lack of progress, whilst the limited success of the treatment interventions provided are partially absolved from such scrutiny.

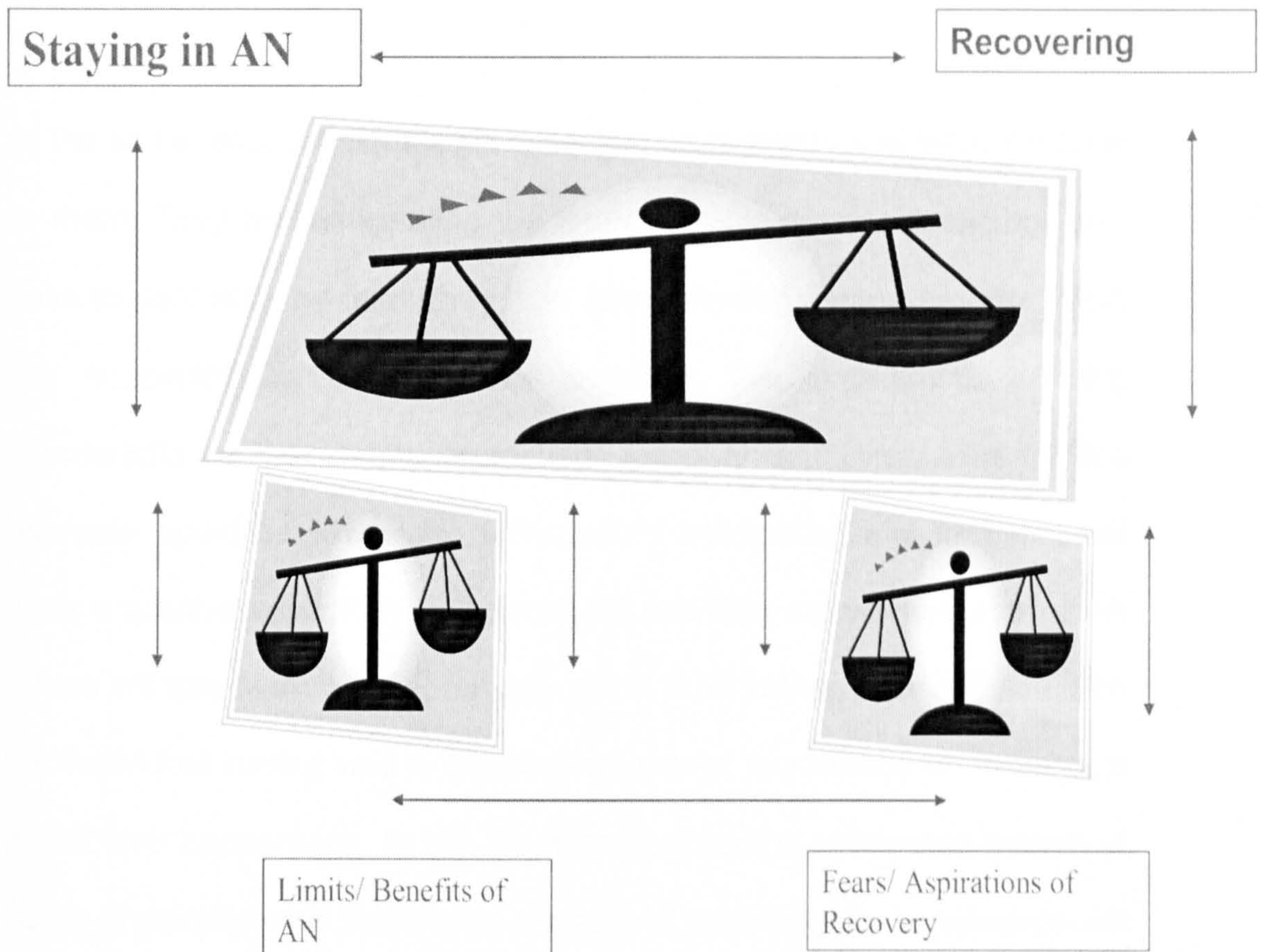
Returning to the Cockell et al. (2002) study for further support to this concept, they point out that the third factor in the decisional balance, the 'functional avoidance' subscale, can be interpreted as serving both a positive and negative function for the individual. It can be positive in that the individual perceives it to be 'helpful in providing escape' (p.370) and negative in that it also means that the individual does not achieve their longer-term goals.

This ambivalence emerges from the participants and is important to the experience of recovering from the insiders' perspective. It contributes to the mismatch in perceptions of the same event between the individual with AN and those without it, with unfortunate consequences. Of further importance for this study is the suggestion that individuals with AN have insight into the 'complexity of their life circumstances' (p.371). This includes the extent to which the individual is aware that the problems (i.e.

burdens) perceived serve a purpose (i.e. benefits), which 'on a deeper level provides a means to avoiding a perceived worse fate' (Cockell et al. 2002, p.371). It is in this perceived worse fate, whatever this may entail for the individual, that will have to be addressed in recovering from AN and I address this in the category *doing what is necessary*. However, the Cockell study only construes it in terms of avoidance of the AN state itself and not the work required in dealing with it, which is a part of recovering. This I believe is a criticism to be levelled at most of the studies quoted so far because their focus has been on looking at the costs and benefits of having the AN as the determining factors when deciding to recover whilst neglecting the challenges posed to the individual by the process of recovering itself. In Figure 3.2 I have drawn the subcategories of this category, how they interact and affect one another. The smaller sets of scales represent the considerations the individuals make around the illness, on the left and recovering, on the right. The arrows indicate the movement of the scales either up or down in response to the decisions made by individuals and whether they support recovery or not. The lower sets of scales can influence each other as well as affecting the larger set of scales above them. Using scales may appear a touch ironic given my subject matter but scales can be tipped in either direction and as such convey the dynamic nature of this construct and how different categories influence one another. The next pages will describe this in more detail.

Whilst reflecting on the illness, individuals with AN have to recognise the destructive aspects of the illness, how it limits their lives as well as acknowledging how it has come to be of benefit to them.

Figure 3.2: Diagram of interactions between categories of, *deciding to recover*



Without doing both, they will not recognise there is a problem in the first place and even if they do without also acknowledging its benefits, they may continue to downplay or even deny the seriousness of the problem. An example would be where the individual is low weight and endangering

their physical health and because the AN is helping them address other issues in their lives they will not act on their physical health. The outcome of these considerations shifts with the change of importance an individual gives to the components of the each side of their debate. Therefore, as they become more physically unwell this becomes a larger part of their considerations than previously. This is particularly the case if it intensifies other limitations such as not socialising with friends.

At the same time, individuals are reflecting on recovery and what it means to them. They are anticipating the likely benefits of recovering but also have to deal with the fears they hold about starting such a process. Both are important to the process because the anticipated benefits counterbalance the fears promoting recovery and vice versa. One example would be where the individual is anticipating that recovery will have a positive impact on their social life and they are worried about how others will see them or whether they will fit in. A further example would be the individual having had a negative treatment experience or comments about their appearance. In this situation despite the anticipated benefit of being physically well, the fear of a return of such negative comments will undermine their commitment to recovery.

However the AN and recovering from it are not separate and they influence each other. The individual with AN may decide that given how bad they are feeling physically the benefits of doing something about it may outweigh any fears they have about what it might take to start

recovering. Alternatively if the AN serves to sustain a relationship with a relative that they value then this may outweigh any concerns about their physical health or any benefits that improving it may bring.

The larger set of scales represents this next level of deciding to recover, where the reflections about recovery and AN come together. Thus a decision to recover based on an analysis of the AN only, may be supported or undermined when the decision based on the analysis of recovery is incorporated. It is at this level that the participants of this study experienced and considered the unpleasant aspects of recovering. These either were anticipated to be part of the recovery process or had been previously experienced by the individual and they influence what the individual will decide to do. For example if the individual is considering having treatment and they have previously had a negative experience of treatment then this is likely to reduce the individuals confidence that it may be beneficial to them. Another participant in this study spoke of not using treatment the first time around and that therefore on returning to treatment she was influenced to try harder to make the most of it. In my experience professionals often focus on the analysis of the pros and cons of the AN and give limited consideration to the recovering process. As discussed earlier this may happen because the normative view of recovery is positive and ultimately worth it and that as professionals we promote recovery. However, its significance lies in how it might influence practice and I will discuss this within my conclusion and its implications.

Figure 3.2 when taken all together represents the construct *deciding to recover* but not its entirety. Participants of the study emphasised another aspect, which has to do with the conditions that need to be fulfilled to start to recover. These conditions were also important to recovery being sustained to its conclusion. I have labelled this aspect *making it personal*, which I will now detail.

Making it personal

You have to want it, you have to want it. You also have to want to change a lot. You have to want the change. You can't have everything you want; you can't have the five star life and an eating disorder. You have to actually want to change. You have to take on what people are saying to you. You just can't keep going you have to change. (P351)

Participants emphasised that the person with AN has to want to recover or the process is unlikely to start and would not be sustained. Recovering is both anticipated to be and is reported as being difficult and challenging by the participants. If the individual is not recovering for him or herself, they will not embark on such a difficult task in the first place. They have to develop a personal commitment to recover. They do this by drawing on their hopes for a life without AN. These hopes will help them to sustain their efforts to recover, particularly when things get difficult. Participants caution against doing it for other people, particularly those closest to them. They predict that such motivations would not be sufficient to sustain the

effort required to recover and can lead to resentment towards the other person.

At the end of the day you control what you eat. It's you and you cant get better for anyone else because as soon as you try you end up resenting that person and if anything ever goes wrong it's the first thing you go back to, the anorexia because you don't do it for yourself (P350)

The individual is solely responsible for the recovering process; they need to be in control of it. If they cede this responsibility to others or wait for others to make them recover, it will not happen and they will stay with their illness.

I'm the only one who can do it. It is a struggle with yourself. (P348)

One exception highlighted by participants relates to when individuals are so ill that others have to intervene through insisting on eating or weight restoration. Participants stated that, at these times, it was unlikely that they would start to recover themselves so they accepted the need for others to act. However, the responsibility has to be returned to them as soon as possible to avoid being pushed too far too fast and increasing the risk of relapse. They acknowledged that others had a role to play (I will return to this later) but the greatest role was always reserved for those with the illness.

Therefore, individuals have to create their own solution. They adapt their own and other resources available to them to manage the recovering process if in order to sustain it. As this participant says:

I know the bottom line is that it is a really funny illness – not funny ha, ha, but it's very strange because it's an illness and yet you want to have it and, at some point, you have to make the decision that you don't want to have it any more. (P349)

Vansteenkiste et al. (2005) examined the motivation to change in eating disorders from the perspective of self-determination theory. They found that the more the individual internalised the need for change, as well as their acknowledgement of the personal importance of change the greater the change that took place.

So at this stage individuals review the AN, its affects on them as well as how it functions for them. They must also consider recovery, its potential benefits and the anxieties they have about what it will bring. The conclusion they reach must be supportive of recovery or they will remain with AN. They have to decide to recover for themselves and not for others or they are likely to fail. What this suggests is that the individual is in a struggle with him or herself as to what to do. They have to engage with complicated and demanding issues if they are to recover. Participants suggest that they value simplicity and predictability, a finding in the literature also, which serves to heighten their anxieties about the demands

of recovering. Therefore in *deciding to recover* individuals examine the limitations and possibilities of AN as well as recovery from it. They must conclude that they have to change if recovery is to start.

As Maine (1985) found in her study of recovery from AN, 'All saw personal responsibility and self motivation as integral to their recoveries. The inner logic of anorexia was impermeable until these shifts began' (p.52) However, deciding to recover is not a one off event and participants were clear that they had to continue to decide to recover and I will cover this more fully within the category *sustaining recovery*. For now the individual with AN must move on to the next stage that of the *doing what is necessary*.

Doing what is necessary

This major category incorporates the tasks that participants say are essential to the recovering process. Although there are, other tasks to recovery these are particularly significant because without undertaking and completing these recovery will not be successful. In addition, it would not be sufficient to complete just one of them without the others, as this too would lead to a limited form of recovery and an increased risk of relapse. Participants found the prospect and experience of these tasks anxiety provoking and daunting which meant that they had to continue to decide to recover in the face of the demands such tasks placed on them. This major construct labelled *doing what is necessary* consists of three categories *repairing the damage*, *dealing with underlying issues* and *re-establish*

control. Table 3.6 summarises the various categories that make up this construct.

Table 3.6: Major construct *doing what is necessary*

Major Construct	Categories
Doing what is necessary	1. Repairing the damage 2. Dealing with the underlying issues 3. Re-establish control 4. Combat the power of the AN

Repairing the damage

I think that obviously weight needs to be restored when you're very low weight and I think this is the same for most people and it has to be done in a safe manner so that you can restore your weight to a healthy weight. (P344)

This participant captures what other participants also emphasised that they must restore their weight if recovery is to occur. This first category *repairing the damage*, relates to undoing the harm caused by the restriction of food intake and/or the other behaviours such as laxative use, vomiting or excessive exercise. This harm is physical, psychological, emotional and social and as such, it imposes limits on individuals. In the category *recognising the limitations of AN*, I outlined how individuals were affected by the AN. Participants spoke of feeling cold, having no energy, being a *'bag of nothing'* and isolating themselves from others. Whilst in *wanting to be more*, participants anticipated the likely benefits of eating more and increasing their weight. AN reduces the resources individuals

have to start and to continue dealing with the demands of the recovering process. One participant talked of not even *'thinking about recovery'* (P346) because of how physically ill she was.

Its impact on the physical and psychological capacity of the individual undermines their efforts at recovering and handicaps them when they need all of their resources to succeed. They have to begin to *repair the damage* if they are to withstand the demands of recovering. To do so they must eat adequately and restore weight towards a more healthy range. This participant describes just how this works.

Once the first few pounds go on you start to feel yes I can do this- and the more weight you put on....like now I have so much more energy, I generally feel warmer. Like before even with the heating on I'd always be cold and have big jumpers on. Now I don't feel like that at all and can walk around in t-shirts and feel fine. You generally feel more comfortable and it is those little things that make you realise that it is actually worth putting the weight on (P345)

The quote also acknowledges how putting weight on helps individuals to keep on recovering because of its positive effects. The individuals capacity to deal with their AN is increased as they become physically healthier. This effect is important because of its role in counteracting the aversive aspects of the recovering process. I outlined the influences arrayed against recovery in the subcategories *acknowledging the benefits of AN* and *fears about recovery*. The benefits, remarked on by the participants to restoring

their physical health act as reassurance that recovery is worthwhile. The next quote outlines how repairing the physical damage will help them to have enough energy to pursue other aspects of their life.

Initially it would be the energy to have a life. Before I came in here I had no energy and that's why I lost a lot of my life... and also when you haven't got the energy to actually do things even if you want to.(P 341)

Ultimately the physical impact of AN is significant and can make it impossible for the individual to function on a day-to-day basis. (Keys 1946) We also know from research that those who restore weight to close to their healthy weight have a better prognosis than those who do not (Pike 1998, Strober et al.1997, Herzog et al 1993) and participants' perspectives concur with such a finding. Therefore for the best chance of recovery being successful the individual with AN must eat and restore their weight.

From the etic perspective eating and improving physical health through weight increase appear self-evident and something to be pursued. However, they are fraught with challenges and fears for the individual with AN. These tasks contribute to the experience of recovering as unpleasant. This is important because it can undermine the commitment towards staying in recovery. Indeed too great a focus on the physical aspects of recovery can undermine the process. In the introduction I discussed the literature and the concerns expressed therein of too great an emphasis on such physical measures of recovery, (Noordenbos & Seubring 2006, Pike

1998 as examples). In a similar way participants warned against too great a focus on physical issues alone and emphasised that other issues needed attending to.

The thing is when you put weight on in here often initially as well your weight can increase massively and your mind can be still however many miles behind and you like I said its not just about weight restoration but also tackling the underlying issues that caused you to lose the weight in the first place. (P350)

Also in the introduction, I outlined how such an emphasis could both underestimate and overestimate levels of recovery. Recovery would be underestimated because progress to recovery is measured only by reference to physical well being and neglects improvement in other areas. Whilst it could also overestimate it, if physical well being is treated as complete recovery in the context of continuing difficulties elsewhere in the person's life. Participants share this misgiving and convey that they need to be *dealing with underlying issues*, which I address in the next section.

Participants stressed that repairing their physical health was a significant component of their recovery particularly in the early stages. This was true for participants who regarded themselves as recovered and those who remained ill. Such a consensus was surprising in that it is unexpected given the commentary on the concept of denial of illness in AN outlined in the introduction. Perhaps as noted by Vitousek et al. (1991) my role as interested researcher as opposed to a clinician involved in their care may

have allowed participants to acknowledge this aspect of recovery without believing they had to act on the insight.

Dealing with underlying issues

If you're in recovery I think you should be working on the issues otherwise you just are kind of delaying a relapse because obviously there are problems why the illness started – it's not just a thing that happens. There are problems that need to be worked on otherwise they'll happen again and even if you think you're recovered at the time it can happen again. (P343)

This participant warns of the consequences for individuals who do not address the underlying issues which contributed to the AN developing. Improving their physical state as challenging as that is, is not sufficient on its own to bring about recovery. Pike (1998) in a review of the outcome of AN states that 'Addressing past trauma is an important issue' (p.471) but recommends that work on such trauma be carried out when the AN is not in an acute stage. Individuals have to address underlying issues, which could have contributed to the emergence of the illness or evolved as the illness progressed. These included dealing with low self-esteem, poor family relationships, fears about coping with adulthood, childhood trauma and other psychiatric symptoms such as obsessions or depression.

Other issues emerged as the AN progressed and an example was the sense of feeling stronger, different, even special because of the response

of others to the illness. Another participant described herself as being '*let off the hook*' (P345) by the AN as she did not have to deal with the expectations of others. The key characteristic in all of the scenarios outlined above, is that the AN helped the individual deal with events which they experienced as difficult in their lives. In a way, this method of dealing with things was not to deal with them, to avoid them through becoming preoccupied with the demands of the disorder. This avoidance is a characteristic referred to in the literature on AN (Schmidt & Treasure 2006, Cockell 2002, Slade 1982) and unless it is dealt with relapse is likely to occur.

Troop & Treasure (1997) in a study of psychosocial factors in the onset of eating disorders found that cognitive avoidance, as a means of dealing with difficult events was associated with the onset and maintenance of AN. In this participants case the constant focus on food and dieting that characterises AN served to occupy all the waking moments preventing the underlying issues from surfacing.

For me it was a way of dealing with things, I don't actually.... The anorexia was the solution. It emerged out of how I dealt with other things and took a grasp that way (P346).

Therefore, any reduction in this preoccupation with food would open the way for the re-emergence of underlying issues, which would demand the attention of the individual. Unless they developed new ways of dealing with these issues, they were likely to relapse into the AN. If they develop

new ways of dealing with them and are supported to do so then they will continue to recover. This next long quote captures what is required to deal with underlying issues and how by doing so it enhanced understanding of what was needed to recover.

For me I didn't realise what it was so I needed to go back years and years and years to find all the little things that had built up to make one big.... You know.... It was like a catalyst. There was like these little bits that all of a sudden.... Or maybe not all of a sudden but over a period of time joined together and that was where my downfall was – not having dealt with them properly.(P347)

The remainder of the quote covers the work involved in dealing with them.

... I was going through the talking therapy and I had to draw pictures and write letters and stuff like that and all these little things came out. Not necessarily that I had to delve deeply into all of them – I just had to acknowledge them and once I had, it became easier to recognise how I was going to recover and what I needed... (P347)

The literature on the coping strategies of those with an eating disorder is also helpful in this regard. It suggests that individuals use avoidance more than do control groups. (Bloks et al. 2001, Troop et al. 1998, Troop et al.1994). However Bloks et al. (2004) in a further study examining coping strategies and recovery in eating disorders found that recovery in AN was associated with less avoiding, less passive reacting more active tackling and more seeking of social support. The facing up to and dealing with their

difficulties proposed by the participants resemble the concepts of less avoiding and more active tackling outlined in the study. Bloks (2004) also found that those participants who remained ill displayed no difference in coping strategies from assessment at follow up. They did not report on any interim stages in the recovering process in terms of coping strategies. A conclusion they reach is that the teaching of coping strategies is likely to be beneficial in helping individuals to recover and to make individuals less vulnerable to relapse. In this study, participants emphasised the necessity of dealing with the underlying issues differently if they were to recover. Avoiding these issues would leave individuals vulnerable to relapse.

There is another aspect to the AN as a coping mechanism. Conceptualising AN as a solution, as Bruch (1985) has done can help explain the individuals adherence to behaviours which are destructive. When AN acts as a solution for individuals it is reinforced by virtue of its success in distracting individuals from the underlying problem. However, it can also come to be reinforced because giving AN up means having to deal with whatever it is a solution to and this is likely to be an aversive experience. Recovering involves not just giving up the solution but also finding alternatives ways of dealing with whatever difficulties exist. Therefore challenging the power of the AN is seen as only a part of the struggle by the participants of this study. They are required to go beyond this and to change other aspects of their lives which if they do not they will not recover.

One possible outcome of this can be to undermine the individual's confidence about being successful in recovering. They see it as overwhelming and beyond their capabilities. When this is the case, they will be less likely to start to recover and may give up early in the process when it is particularly difficult. (It is difficult throughout). It is important therefore to assist the individual to review their perception of the recovering task. For the individual doing so provides an opportunity to reflect on the recovering process and how they might be helped achieve it. It will also allow for the identification of any unrealistic demands they are making of themselves. It can allow also for the identification of steps that have been taken and the acknowledgement of interim success, which reinforces continued recovering. For those trying to help it offers the opportunity to empathise about the nature of the task to be undertaken and reduce misunderstandings. Participants reported that others often underestimated the task of recovering which leads to demands being placed on them that they feel unable to meet. A consequence of this was that it could lead to a lack of positive comment on or recognition of what they had achieved. Avoiding these pitfalls in an already difficult process was seen as beneficial by participants and helped them to recover.

However, for professionals there is a further danger that of neglecting the power of the AN in the treatment process which will likely result in a lack of progress. Beumont and Vandereycken (1998) when discussing the challenges and risks for professionals describe a scenario where the professional may 'ignore, minimise or even trivialise, the eating disorder

because 'the real issue is supposed to be something else' (p.15). They argue that this is because the professional does not understand the nature of AN and that you have to deal with the disorder just as you would if you were dealing with 'factors maintaining the drinking of an alcoholic' (p.16). They go on to caution that the pursuit of the secret reason neglects the serious impacts the AN has on the individuals life both physically and psychologically. Pike (1998) in a review of the long-term course of AN also cautions professionals not to regard the symptoms of AN as 'simply symbols of underlying issues' (p.471) and suggests that it is critical that the professional be aware that 'whatever caused the illness may not be what is maintaining it' (p.471). It is also important to acknowledge how the symptoms of the illness take on a life of their own which can have serious implications for the individual with AN. Such advice is echoed by participants emphasising the need to address the hold the AN has on their lives in order to sustain the recovery process.

Participants when describing the aversive aspects of the disorder list not only the physical effects of their starved state but also the psychological effects that can only be addressed via their physical recovery. Interventions, which neglect this in favour of a search for a psychological cause, run a high risk of failing to address the deficits associated with the AN. However, this is not to say that underlying issues are not relevant to the recovering process. Beumont and Vandereycken (1998) note that such issues exist but that the relationship with the eating disorder may not be direct. What this does suggest and which emerges from the accounts

of participants is that recovering is a complex process that requires attention to a number of areas at the same time if it is to be successful. Learning skills to manage their emotions and getting support from others are helpful at this time.

A separate but connected issue for participants arises if they do not address these underlying issues. When faced with situations previously dealt with via the AN there is a risk they would use other unhealthy means to manage their lives such as alcohol or drugs.

I'd see myself as weight recovered, but you have to understand what got you there in the first place. I suppose the way I see it is as an accident waiting to happen. I have had problems in the past with other things – partying and drinking a lot – overdoing exercise. They were my chosen coping mechanism at the time then anorexia came along and I suppose without the others putting the pieces together and finding out what was going on, next time I could be a drug addict or something else that just comes along.(P349)

For those participants although they would no longer have symptoms of AN they would not view themselves as recovered because they are swapping one unhealthy solution for another. They avoid dealing with the issues and do not achieve the recovered status they are seeking as a result. Recovering from AN is more than not having the symptoms of AN it also requires change in how the individual deals with difficult issues which arise in their lives.

Before moving on, I want to draw out another aspect of recovering which participants revealed in their accounts. They emphasised that if physical health is the only focus of recovery and underlying issues are not addressed then this would lead to an unstable situation and result in either resistance to change or relapse. The opposite, addressing only the underlying issues without improving the physical state would result in a similar situation. The individual would be too physically compromised to benefit from any psychological work undertaken.

The first condition of improving physical health with no attention to underlying issues I have observed in my clinical career. Amongst my colleagues, the outcome of such an approach is described as the revolving door syndrome. Individuals with AN are admitted to eating disorders units, gain weight and are discharged only to return after losing the weight some months later. Another scenario is when the individual, aware of the focus on physical symptoms as measure of recovery literally eats their way out of hospital and no other work takes place. This participant captures this scenario.

Yes – I think the first time, maybe the first I didn't really want to recover. Maybe I said I wanted to but I don't think I did. Now I look back and I knew that when I came out I would immediately go back to restricting. (P342)

The second condition I have less direct clinical experience of but the literature holds some cautions about it. The literature on avoidance as a

copied strategy outlined above, alongside Keys study (1946) and some recent work on emotional processing at low weight (Treasure et al. 2005) all suggest that neglecting the individuals physical well being is likely to have a detrimental effect on the successful outcome of any psychological work. It is important to acknowledge this connection between the tasks for a number of reasons.

First, change in one will affect others and this has to be considered when instigating action so that all of its impacts can be considered. Second, it emphasises the need to address a number of areas in the recovering process both for the individual with AN and just as importantly for those trying to help them. Third, it reinforces the holistic nature of the recovering process and that reducing it to categories such as physical or psychological can give a false sense of its overall nature. This interrelatedness is a common characteristic throughout the study and needs to be accommodated into any theory which seeks to explain recovery from AN. I will therefore return to it in my conclusion.

Re-establishing Control

Dealing with the power of the AN is a necessary task and a concept which is linked to this is that of 'control'. Participants spoke of control in many ways and appeared to describe both a sense of control and loss of control depending on the context. Control has been 'hypothesised to play a natural course, variability and treatment of AN'. (p.499 Surgenor et al. 2003). Bruch (1981,1978) described the search for control as a means of

solving a sense of powerlessness brought on by early experiences whilst Garner et al. (1985) suggest that it is the construct of control that differentiates AN from other eating disorders. Lamoreux & Bittorff (2005) suggest that in contrast to other mental illnesses destructive impact on a persons sense of control AN provides the individual with a sense of control. They also suggest that as a result, this will influence the process of recovery and the findings of this study support such a suggestion. The redefining of the meaning of control is necessary because of how the participants and the literature give it a central role in AN.

For participants the AN is first experienced as a way of being in control in circumstances where the individual feels they have no control or are disempowered. If they cannot control anything else, they can at least control what they eat and how they look. This initial sense of control can also arise from the discipline imposed by the AN and the rigidity it demands. Earlier I spoke of the sense of control reported by those with AN as part of the benefits they associated with it. Here participants spoke of feelings of being unable to control the AN even when they wanted to. The following quote captures this dilemma.

When I was low weight the choice wasn't mine, I was out of control and I couldn't control it. Though it started as my way of controlling it, it became out of control. Then I couldn't pull it back on my own. I needed to go in as an inpatient. I kept telling myself I was going to pull this up, I'm going to eat this, eat that, but it never happened. I

needed the help then but it was down to me whether I chose to get better or not. (P343)

However, as the individual becomes unwell physically the sense of control is eroded and they feel out of control. The aspect of control that relates to 'choice' is gone, as they no longer feel able to choose what to do and this can lead to others intervening to make the decision for them. In order to recover they have to re-establish a sense of control that is not dependant on the destructive control afforded by the AN. This is not an easy task as illustrated by this next quote which speaks of how the requirement to 'let go of' the sense of control provided by the AN interfered with efforts to recover.

I just took it a stage too far, but then it was something that I'd taken control of and worked for – I resisted letting go of that because it was again the control thing. I didn't want to let go of the control I had. (P345)

For some individuals it represented a way of creating a sense of power and control in the context of feeling powerless and out of control emotionally. Recovering meant they would feel empowered.

Sometimes I feel quite sort of – empowered. (P342)

Part of redefining control related to re-establishing what they saw as the proper mechanisms for managing their food intake and hunger.

The control thing goes a bit warped and I'm controlling my food for the wrong reasons so recovered and control would be ... Almost like my body having control of my food intake as opposed to my mind. If that makes any sense (P 348).

Where individuals are unable to act to change the situation because of the power of the AN others will press for change. In a sense this is the outcome that their pursuit of control was designed to prevent as their situation deteriorates to the extent that others intervene and insist on treatment. This can give rise to two scenarios both of which complicate matters for the individual in recovery. The first is where the individual agrees to treatment and cedes control to others in a considered way. This results in less opposition to treatment interventions and the individual retains the sense of control they value. The second is where they are unable to cede control and this is taken from them through the use of mental health legislation. In such circumstances a battle for control is likely to emerge between the individual and those seeking to offer treatment. (Lancely & Travers 1993). However, research into compulsory treatment is equivocal as to how it affects the individual. Ramsay et al. found that 50% of patients treated compulsorily found it helpful at follow up and Cockett et al. (1992) found that patients treated compulsorily were generally positive about their treatment with hindsight. However, registering the other sides to these findings, that 50% found treatment unhelpful and that some were not positive provides a different perspective on these studies. Also given the involvement of the researchers in the delivery of the treatments in

each study raises the possibility of bias in the findings. Szmukler et al. (1981) in a broader study not involving people treated by the service in which he worked found that those treated compulsorily had a long-term unwillingness to engage with treatment services compared to those who were not. Such findings serve to underline the caution required when intervening to help the individual with AN particularly if it involves reducing the sense of control the individual has.

However, another aspect of the concept of control that emerged relates to the process of recovering itself. Participants reported that seeking to regain control through eating more or engaging in psychological treatment can result in initial relief followed by thoughts and feelings which are anxiety provoking.

When the weight does start to go on – to start with it is really scary and you kind of lose control of something that you have had tight control of all the time and you feel frightened that you're going to lose control and not stop putting weight on (P345)

The emergence of these fears and anxieties led to a desire to bring them back under control which the individual can achieve through a return to AN. Participants underlined the importance of this to recovering because it could cause an individual who embarks on treatment to withdraw at the point when the sense of control they value is threatened. There are a number of points, which arise from this. One, the changing meaning of 'control' across the recovering process requires flexibility and the ability to

adapt from both the individual with AN and anyone who is helping them. A second is that interventions need to be agreed with the individual to reduce the sense of loss of control that will arise. This participant conveys how their sense of control is tenuous and usurped either by others or by the illness when they intend to retain the control for themselves.

I think I don't feel very in control during it because I think sometimes the illness takes over or other times some of the people who are trying to help take over. I think I am quite determined to be doing it by myself. (P343)

It is the latter point that is important in that for individuals to recover they must re-establish a healthy sense of control. This participant acknowledges just such a shift in that they have now developed a different understanding of control as they recover and that they used food to exercise control in other areas of their lives where they didn't feel in control;

It's only really over the last year – 18 months that I've actually realised what it meant to control. I used the food because there was other stuff in my life that I didn't feel I could control (P342)

There is another aspect to control in recovering from AN, and it relates to the management of the whole process. Participants emphasised that it was important to their sense of control that they were able to manage how the recovery was going.

It was a physical and mental thing that happened to me and it was on a physical and mental level that I had to recover from it, which was hard because it had to work hand in hand with one going one way and one going the other way. They didn't always tie in with each other but as soon as I found a way of trying to keep those two together it all sort of looked up and got more positive for me. (P347)

This was important because the individual had to keep within their own tolerance levels even if this was difficult with '*one going one way and one going the other*'. Once they had found their way of tying the progress in the physical and mental areas together then things improved for them. A consideration, which flows from having control, is that individuals have to have as much responsibility for the whole process as they can tolerate if it is to have the best chance of success. Driven too fast or too slowly by others and the individual will not recover. Pursued too quickly or too slowly, individuals will learn what is required and adjust it to reflect their own abilities to tolerate its demands. The only exception to this is when the individual either cedes responsibility to others or has it taken away due to an immediate threat to the individual's life. Even then recovery is more likely to be supported if they are collaborated with in their treatment and responsibility restored to them as soon as practicable. One way in which this could be achieved was if the individual was allowed to manage the whole recovery process. This long quote from a participant begins with a sense of how this might be done and goes on to outline the benefits of her doing so.

The thing is when you put weight on in here often initially as well your weight can increase massively and your mind can be still however many miles behind its not just about weight restoration but also tackling the underlying issues that caused you to lose the weight in the first place so almost like when you put on the weight you give yourself a trigger of what caused it in the first place and that's why like I know in my recovery I am aware that I have to let my mind catch up with my body before I can carry on so that's why I am quite aware that it could take much longer than I first anticipated. But its better to be safe than sorry. You know, because I'd prefer to do it comfortably and properly rather than pretend and go straight back into denial again, pretending I'm better and I'm not (P350)

If she does not manage the process there is a danger that it will lead to pretending to be well which leads to denial of the problem and pretending that she is better. The outcome of these set of circumstances are that she will not continue with recovering and is likely to relapse. The self-awareness that is obvious in this quote is important to the recovering process as it informs the individual of their capacity to tolerate the demands of recovering and increases the likelihood of success. Indeed the components of this category in a similar way to those in *deciding to recover*, interact and influence one another leading to an alteration in the individual's response to the recovering process either towards further recovery or away from it.

Responding to such a complex and interactive set of circumstances is a challenge for the individual and is likely to be best managed by them. Maintaining a balance between the various necessary tasks is important also as any one alone is not sufficient to guarantee recovery. It is here that the individual emerges from what are the tasks which are common to all with AN. Each individual will undertake their necessary tasks in their own unique way bringing their particular set of skills abilities and weaknesses to bear on it and carving their own journey. This participant highlights how such an approach could benefit them.

I suppose if you're talking about recovery for you rather than being told what recovery is then it makes it more something you have to do – something more personal to you and that you can challenge and tackle in yourself rather than being told 'this is what recovery is – this is what you've got to do – this is how it's going to be'. If you're asked what recovery is to you because everyone is individual, then you can say this is what it means to me, this is what I've got to do to get towards recovery and to be recovered, rather than being dictated to. (P344)

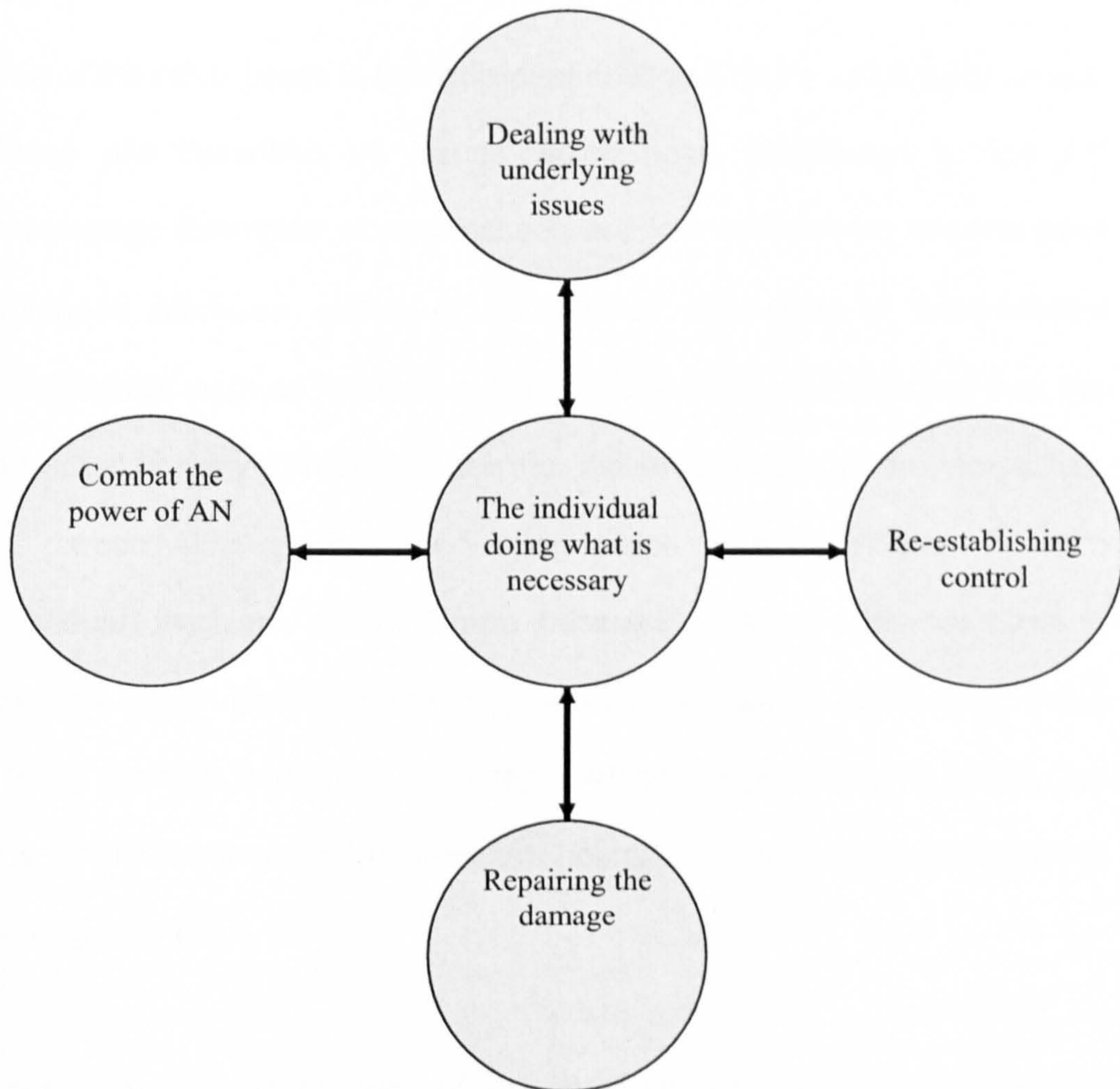
The individuality and uniqueness of recovering emerges from the participant's accounts. Each individual will share the commonalities of the journey which are the necessary tasks outlined above but will progress through them in their own unique way determined by their personal context.

Summary of category

Figure 3.3 is a diagrammatic representation of how this aspect of recovering works. It is deliberately radial in nature to convey how each of the activities named in the arms is necessary for all individuals with AN. The bidirectional arrows are also designed to convey the sense of constant flow of influence back and forth and through the system which contributed to or not the progress of recovering through doing what was necessary. The central circle represents the individual with AN engaged with the necessary work and they have an executive function in that they manage the process. The work done in each spoke influences the centre and by doing so influences all of the other spokes. There is a constant flow through the system, which sustains the recovering process. This is important as participants emphasised how interlinked these aspects were and that if one aspect was neglected this was likely to undermine the whole process of recovery. Outlined below is a detailed account of how they link together which emerges from the findings. Having decided to recover the individual must now engage with *doing what is necessary*. They must start with *repairing the damage* that has been done to them by the AN in all areas of their life. They are starved and underweight and whilst like that are denied their full potential to help with the recovering process. They are terrified of any weight increase and therefore find the prospect of eating more food daunting. However, they have to start here for without improvement in their physical state there will be no change in the other areas of their lives. Participants of this study were clear that

when they are physically compromised they have little energy for other activities.

Figure 3.3: Interaction between subcategories of *doing what is necessary*



Once they had begun to address this by eating more, they then have to consider starting work in the other areas. When considering this work participants warned against too rapid a progression in one area. If this happened it was likely to cause the individual to stop recovering, as they

felt overwhelmed by the change and unable to cope. There was an acknowledgement that improvements in physical health would progress more quickly than in the other areas such as the psychological and social. This was due to the direct impact of food on the person's physical well being and the more complex work often required in those other areas.

One of the other areas is the individual dealing with the *underlying issues*. These are described as issues which have contributed to the AN developing. Examples of such issues are low self-esteem, trauma from childhood such as abuse or bullying or difficulties in interpersonal relationships such as family members. If these are not addressed then the individual is likely to relapse back into the AN because of their impact on the person. Although these underlying issues would be different for each individual, they are included here because all those with AN have to address some type of underlying issue. Participants addressed these usually through treatment or therapy, which supported them to develop new understandings of the events, or helped them to develop new skills in dealing with them.

These activities are not without danger to the individual as they come to terms with what are often distressing and difficult events. Participants feared what this might bring and some experienced it as aversive. However when undertaken successfully (I will address how this happens later in the study) it had the effects of increasing their confidence that they could recover as well as improving their self-esteem. Both of these are

important given the earlier discussions about the role of low self-esteem in AN and the difficulty of the task faced by the individual who is recovering.

The *re-establishing of control* is necessary because it plays a central role in the disorder as described by participants and the literature. For participants the AN is first experienced as a way of being in control in circumstances where individuals feel they have no control or are disempowered. If they cannot control anything else, they can at least control what they eat and how they look. This sense of control can also arise from the discipline and rigidity imposed by the AN on an individuals behaviour. Then, as individuals become physically unwell, the sense of control is eroded and they lose the sense of control. In particular, that aspect of control, which relates to 'choice', is lost, as they no longer feel able to choose to act against the disorder. They are unable to act to change the situation and this leads to others insisting that the individual go in to treatment. Such intervention by others if resisted by the individual will result in greater dangers to their health and more desperate efforts on the part of others to intervene to solve the situation. Part of *recognising the limitations of the AN* is accepting that individuals need the help offered and forms a part of the recovery they want.

Individuals must retake control in order that they can choose how to live their life. Through engaging with the *necessary tasks*, they get an increased sense of control from actively doing something about the issues in their lives. They must also have as much responsibility for the recovery

process as they can tolerate to give it the best chance of succeeding. Driven too fast or too slowly by others and the individual will not recover because they will feel overwhelmed by the demands of the process. Whereas, if they are in control of the pace of recovering in order that it reflects their ability to tolerate the demands of the process this will result in a better outcome. There are two exceptions to this, one when individuals cede responsibility to others and two when control is taken away due to an immediate threat to the individual's life. Even then, recovery is more likely to be supported if a collaborative approach to helping them is adopted and responsibility restored as soon as practicable.

Combating the power of the AN

As outlined in the introduction AN is a serious mental illness with the highest morbidity of any psychiatric illness (Nielsen et al. 2001), whose outcome has not improved in the second half of the twentieth century (Steinhausen 2002) and for which there is little evidence to guide treatment (NICE 2004). These statistics illustrate the nature of the illness, and the limited contribution, so far, of treatment models to help with the recovery process. In a sense, these stark facts also shed light on some of the difficulties faced by individuals when trying to recover. This is one aspect of a group of themes that I have labelled the *power of the AN*. Alongside this participants outlined other aspects of this *power*, which have to be overcome if they are to continue to recover. Table 3.7 summarises the main components of this subcategory some of which I found surprising and are unique to recovery from AN.

Table 3.7: Category combating power of AN with its components

Category	Themes
Combating power of AN	<div>1. Managing the initial symptom increase in recovery.</div> <div>2. Addressing demand to stay true to AN identity</div> <div>3. Overcoming the intensity of the disorder</div> <div>4. Coping without the functionality of AN to the individual</div>

Managing the initial symptom increase in recovery

As participants described this theme, I was aware of how surprised I was by it. They were describing the AN symptoms as increasing in intensity in direct response to the individuals efforts to change. This participant captures this effect.

And it seemed to be the more I tried to recover the harder it was to climb back up again the more obsessional I became, more afraid, the more bad foods I would cut out things like that ahmm and the less feelings I was able to cope with and when I say it seemed very strange to me that I was trying to attack it I seemed to be getting worse. It's kind of like it grabs on to you for all that it's worth, it's got a hold of you and it won't let go and you've got to smash out of it and that's hard but I think the more I started to understand that that's when I started to get a bit more outside help (P351)

The AN appeared to the individual to fight back against the changes they were trying to bring about. They experienced an increase in the frequency of thoughts urging them to return to AN behaviours such as cutting back on food. In a sense the AN was reluctant to let go and as the participant describes *'it grabs on to you for all that its worth'*. The result of this is that it challenges the commitment to recovery is experienced as aversive by the individual. One consequence for this participant was that having experienced this during her recovery she now had more empathy and could understand why people might falter in their recovery at this stage. Another author Bills (1993) described that in recovering she would dream about overeating. She was relieved that it had not happened when she woke up however she also experienced this as feeling almost *'overwhelmed by the power of the disorder'* (p.67).

Within the professional literature, there is no direct reference to this phenomenon. However, within the guidelines for the treatment for eating disorders produced by the National Institute for Health and Clinical Excellence (NICE 2004) there is recognition of an increase in risk at times of transition. The guidelines recommend that professionals treating individuals with AN be aware of and plan for such an increase. The specific context being that those with AN often become more distressed when they start to restore weight. This recognition of the increased demands on the individual at this point in their recovery reflects the experience of the participants in this study.

Addressing the demand to remain true to the AN identity

A second area, which emerged from the participants' accounts, relates to individuals experiences of acting in ways, which they see as not in keeping with their anorexia. They described how driven they felt by the AN to adhere to certain patterns of doing things and ways of spending their time. This participant speaks of the demands they experienced to remain true to the AN and how this could limit what she was and was not allowed to as a result.

So its like the anorexia almost had a life of its own in some ways you began to feel like you were committed to it you couldn't do things, that didn't seem in keeping with it, so you lost a lot of weight then it was harder to go and eat because it didn't fit the picture. (P350)

In a sense individuals were describing a valued identity, a set of rules to live their lives by which when broken result in feelings of letting themselves down. When they are recovering, they have to change these rules and tolerate the feelings they have. Participants can experience recovering activities as wrong or as a failure, which in turn leads to negative feelings about themselves. This leaves them vulnerable to a return to AN as a way of dealing with these feelings. To continue recovering they have to overcome this and tolerate the initial surge of emotions they experience. Participants did indicate that the initial period in recovery, without stipulating how long that might be, represented an intense period in terms of emotional activity and that getting beyond it was a positive sign for them that recovery was progressing.

Overcoming the intensity of the AN

The power of the AN is also evident in participants descriptions of how their lives were reduced to just being about food and weight. This led them to neglect other areas of their lives. In a sense they were completely consumed by the AN and did not have time for other activities;

Being anorexic is like putting all your eggs in one basket – the only thing that matters is losing the weight and you become increasingly tunnel visioned and you drop friends and everything else. It's just all consuming. (P349)

Participants described not having time to think about anything else, as they are preoccupied with the demands of the AN. Planning their days to avoid food intake and to mitigate the effects of any that could not be avoided through over activity or purging. It seemed also to participants that cruelly, they were plagued by thoughts of food when all they wanted to do was to forget about it. Contributing factors to this emerged from the Keys study (1946), referred to earlier in which participants were deprived of adequate amounts of nutrition over a period of six months. Participants of that study spoke of becoming obsessed by thoughts of food and of losing all interest in other areas of their lives. Human beings denied adequate nutrition in whatever circumstances obsess about food as a response to their starved state. In the case of the participants in this study, this contributed to the difficulties faced in trying to recover from the disorder because it reduces their capacity to meet the demands of the process. This is linked to the deterioration in physical and psychological

health outlined within *acknowledging the limitations of AN* earlier in the thesis.

Coping without the functionality of AN

Another theme is related to the category *recognising the benefits of AN* within the major construct *deciding to recover*. The AN can be functional to individuals (Gale et al 2006, Cockell et al 2002, Serpell et al 1999) as I outlined in that category so in recovering the individual must relinquish these benefits. In doing so, they face events and circumstances in their lives, which have previously been managed via the AN. These events bring to mind the benefits which the AN and how it has helped them to manage things that they fear. They must now find alternative ways to deal with these events and in the search to do so are exposed to uncertainty and emotions in their lives. This participant outlines how she is pulled by the desire to achieve other things in her life but is also drawn by the familiarity and certainty of the AN;

It's like recovery – not recovery– and if you recover you've got the things you're looking forward to like going to university, having a different life and doing things people expect you to do. But then if you don't recover you're being pulled the other way by the strong part of you that says – stay like this – you're secure like this – you've been like this for years why would you want to change – why would you want to alter. That part just pulls you stronger that way and you can't listen to the healthy part going that way. (P344)

Thus the certainty and predictability of AN is contrasted with the uncertainty and unpredictability of life without AN as perceived by those with the disorder. The security AN provides is experienced as preferable to the insecurity anticipated without it.

These four sub categories relate to the impact of AN on the individual and their efforts to recover. The AN is an all-encompassing illness taking up every available aspect of their lives and squeezing out any competing interests or relationships. It is an illness with little to guide the individual as to how to get better and for which treatment has been relatively unsuccessful. Having decided to recover and made those first steps participants report experiencing a backlash from the AN in response to the change. I am surprised by this as the implication is that interventions to give up the AN can lead to an increase in its symptoms. The AN increases in intensity at least initially and individuals feel as though they are failing because of the demand to remain true to the AN. Their efforts are undermined by the grip of the illness on their lives and they have to develop new ways of dealing with difficult events. They have to deal with this aspect of the illness or they will not recover. Participants described the AN as being a part of their identity as being a part of them. It provided a set of rules to live by, which reassured the person. However, it was also destructive undermining their health and isolating them from others.

Participants in this study came to deal with the power of the AN through eating and engaging in therapeutic work which challenged their thoughts

about food and weight. They reported that when they kept eating this helped them to develop a sense of pride in their ability to resist the AN and continue to recover. They also gathered information about starvation and its impact on people, which highlighted the risks they were running. They had to keep on deciding to recover and did so by drawing on their *wanting to be more* whilst anticipating the benefits of not having AN. They sought out support from others and accepted the help offered. None of the participants who described themselves as recovered had done so without professional help but this may be a reflection of the sample of the study as Woods (2004) has described recovery from eating disorders without treatment.

Lamoureux & Bottorff (2005) in a grounded theory study of individuals who had recovered from AN and the views they held about the recovering process, outline a similar theme. The authors describe how recognising the 'anorexia mindset' and then dealing with it through the use of internal or external resources helped the participants to recover. The authors labelled this theme 'Gaining a perspective by changing the Anorexia mindset' and suggest that this enabled the individuals with AN to recognise how the AN functioned and how it had limited life. The authors concluded that it was essential that participant's thinking about AN had to change to successfully recover from the disorder.

In this category just as in the others the subcategories affect each other and by doing so influence the recovering process. Without addressing the

power of the AN individuals will be more likely to relapse in order to cope with the difficulties they encounter whilst recovering. To deal with this power individuals have to develop themselves and their skills in managing unexpected circumstances and in interacting with others.

Just as in *deciding to recover*, the individual engaged in *doing the necessary tasks* is becoming more aware of himself or herself. This is because in meeting the challenges of the recovering process, they have to explore their personal history and address the issues, which lead to the development of the AN. In recovering, the individual chooses the tougher option and gains a sense of achievement as a result. This had previously been attached to losing weight. In learning more about how to control their lives in a healthy way and become empowered through choosing to continue to recover. All of this contributes to the increased self-awareness which is part of the process of recovering and which in turn helps to sustain recovering. However, beyond dealing with their personal issues and developing a healthier sense of control there are other aspects to recovering and the next section, *building a life without AN* will address these.

Building a life without AN

The recovering activities outlined so far illustrate what participants were keen to emphasise that recovery involved more than not having the symptoms of the illness. It involved more than getting better in the usual sense of that phrase and had to include changes in all areas of their lives.

They must expose themselves to new experiences and learn what their tolerance levels are for such experiences. They have to cope with this without the AN and manage the uncertainty and complexity of life. Contained within this category are two subcategories those of, *taking on new roles* and *getting support from others*.

Table 3.8: Major construct *building a life without AN* and its categories

building a life without AN	<div>1. Taking on new roles</div> <div>2. Getting and using support from others</div>
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Taking on new roles

You replace it (AN) with a social life and friends and work and enjoyment and fun – all of those things – that is how I would see a healthy fully-fledged recovery. (P349)

In this subcategory, participants speak about the nature of recovering from AN and how it differs from the normative sense of recovery. The normative view of recovery, where the absence of symptoms is sufficient to signal recovery is too narrow for the participants. Instead, their recovering required that they do more than this and address all areas of their lives. If they did not then they would be more vulnerable to relapse. Individuals emphasised that recovery involved ‘*getting a life*’ (P345). Table 3.9 below outlines the codes, which make up this subcategory.

Table 3.9: Category of *taking on new roles*

Subcategory	Codes
Taking on new roles	1. Developing relationships with others 2. Occupied with other tasks

Developing relationships with others

An essential part of recovering for participants was to address their interpersonal relationships. As outlined when discussing the category *deciding to recover*, relationships with others suffer when the person has AN. This happens because of the impact of the AN on how they interact with others. They become increasingly isolated to avoid situations where they may feel under pressure to eat. They are physically and psychologically compromised because of their starved state with no energy to maintain relationships. In addition, others are often perplexed and distressed by behaviours, which to them appear illogical and self-destructive. In this isolation the AN would ‘grow’ (P341) taking over more and more of their lives and relegating interactions with others to the margins.

The consequences of this situation influence individuals and also those closest to them. Any relationship they have when ill is largely determined by the demands of the AN. Individuals have both less access to and feel less deserving of the support they could get from others to help them

recover. They are also aware of the distress caused to those closest to them by the AN.

Its been really hard for them to see how ill I was and then they fought it all the way with me to try and get the weight back on. Um... I hate myself having done that to them. (P345)

Recovering means that must develop their relationships so that they are more connected to other people. They must play an equal part in their relationships and not place others needs first. As outlined in the subcategories of *fears about recovery* and *dealing with underlying issues* achieving this is complicated by fears they have about fitting in, of not being good enough and about how they will cope without AN. It also involves exploring aspects of their identity that they have not experienced before such as their sexuality. They must seek engagement with others to enable them to test out the beliefs they hold and to receive feedback about how they are as a person.

Participants did this in different ways. They went out, met others, and had to be proactive in developing relationships otherwise nothing would change. They were responsible for making things happen because no one could do it for them. The benefits of doing so can be seen from the quote below. Time spent with people without AN means exposure to lives being lived differently and to feedback that is not contaminated by the disorder. This results in individuals feeling encouraged to keep recovering.

Being with friends and seeing what they do and seeing what I'm doing – wanting to do what they do and being round friends that also makes you want to keep recovering. (P348)

However, developing relationships they experience as challenging because it involves other people who have needs and make demands. Often participants felt unworthy of contact with others believing themselves to be worthless and this made engaging with people difficult.

I had the difficult part because at that point I would have been happy to sit back and say just leave me. Let me rot sort of thing. I don't deserve help even. That is how I felt. (P347)

Yet they had to persist in building their social life and relationships if they were to recover. If they have managed to retain relationships with family and friends then these are important to the recovering process. Sometimes developing those relationships involved putting distance between the individual and a close other. As this participant notes,

Correcting family relationships, correcting boundaries in family relationships, it's just never ending really so it's just a constant hard work. So my mum, we were very close, perhaps too close in that she was controlling so part of my recovery was rebelling against that but also she's my mum and I love and need her as well so there is conflict there. (P351)

She had to renegotiate her relationship with her mother and in doing so run the risk of jeopardising the relationship that existed which she valued. By doing so, she would create appropriate boundaries in their relationship giving her more space to be herself. In a way, individuals have to acknowledge their own needs as well as those of others and not resolve this dilemma by relegating her own in favour of those of others. Paradoxically individuals become more independent in the context of their relationships. In new relationships where the other holds an understanding of the individuals predicament, offers support and continues to treat the individual as a person and not as a label reflect the conditions likely to support recovering. Other participants spoke of how support with the way they thought about themselves, gathering information about relationships, individual and family therapy as well as '*just doing it*' (P347) helped them to develop relationships.

The literature in eating disorders endorses the role of interpersonal relationships as important in recovery (Gale et al. 2006, Cockell et al. 2002, Serpell et al. 1999, Herzog et al. 1993, Beresin et al. 1989, Maine 1985). Many of these studies highlight how the development of trusting and rewarding relationships are often the key to helping those with AN to recover. The literature is less equivocal about the benefits of any therapy per se (NICE 2004, Steinhausen 2002) but there is some evidence that supportive psychotherapy in adults, (McIntosh et al. 2005) and family/systemic therapy in adolescents is beneficial (Lock et al. 2000). I will not address the role of professionals in this section but will cover it under

the subcategory *getting support from others*. I will now outline another important aspect of recovering which participants identified.

Occupied with other tasks

Participants were clear that developing a worthwhile and meaningful life was an important part of recovering. One of the ways they did this was to involve themselves in education or work. Individuals with AN are often characterised as high achieving perfectionists and this has been nominated as a risk factor for the development of the illness (Cooper et al. 2005) and needs to be addressed in treatment programmes (Fairburn 2005). In my clinical experience, I have worked with individuals who achieved excellent academic results whilst very ill. I have observed them being treated as valued employees right up to the point they are no longer physically able to do the job. In these circumstances the job or academic activity appeared to be a part of how individuals sustained their AN distracting them from thoughts of food and providing a sense of the ordinary and nothing being wrong. However, the impact of the AN usually became so great that there is no time or energy for a job or college course. This contributes to greater isolation from other people which as we have seen is one of the conditions where AN becomes more established.

Participants insisted that having other activities was essential to recovering and that without them it would not happen. The type of activity was different for each individual and could change over the time course of recovering. It meant that participants had to expand their activities into

areas they had neglected, abandoned or avoided as the illness took hold. Participants conveyed the struggle involved in recovery from AN as they battle with facing up to previously avoided challenges. Using work as an example some individuals benefited from any type of job whilst others stated it had to be one they regarded as worthwhile. Securing a job is beneficial to the individual in a number of ways. One is that it builds the individuals sense of self worth through providing a role they value and they are rewarded for doing the job. Two, having money of their own and not being dependant on others for this is another reinforcing consequence of employment. Three, it increased the chances of meeting other people, interacting with them and provided opportunities to socialise. The activity extended for some participants to include university or college courses if this helped them achieve their goals.

Participants remarked on an aspect that is best described as *filling the space*. By this, they meant that being involved in activities they were using up time during the day. By doing so there would be less room for the AN in their lives. In a sense by not being isolated from others, by being preoccupied with other tasks the space into which the AN could grow was reduced. In addition the amount of space available for activities not associated with the AN increased creating opportunities to be different. If they took these opportunities and 'filled' them with meaningful activity then further recovering was supported. Therefore being occupied by other tasks served to protect participants through reducing the likelihood of relapse.

The impact of the above could result in two polarised outcomes one supportive of relapse the other supportive of recovering. Individuals who do not engage in behaviours in keeping with the AN, (as previously mentioned in the subcategory, *dealing with underlying issues*) experienced guilty feelings, which had to be overcome to prevent relapse. However, acting outside of the AN could also lead to the individual feeling proud of their ability to resist the power of the disorder. In these circumstances recovering is reinforced and further resistance to the AN is likely. Another significant consequence of behaving in this way was whilst engaged in the activities participants noted that they were getting to know more about themselves.

Yes. I have learnt a lot about myself (P347)

This increased knowledge and self-awareness enabled the individual to have more confidence in what they did and what they wanted to do in the future. This confidence in turn contributed to their ability to resist the AN and to take on other challenges in their lives. This synergistic interaction meant that recovery is reinforced because the more they came to know and accept themselves the more committed they became to continue to recover. This work is not easy, can lead to individuals feeling anxious and becoming overwhelmed by the challenges they face. As such, it can also contain circumstances that contribute to a relapse if individuals are unable to manage the demands it poses.

In describing the development of their self-knowledge and awareness participants spoke of how there would be 'more of them' around and that 'they', meaning their personality would take up a greater amount of space than they had done previously. In contrast, when they were ill they try to take up as little room as possible. This participant recounted an encounter with someone who had known her when ill and when recovered. She recognised the irony in this situation when her friend commented on her development as a person in the time she had known her by using the word 'grown'.

Somebody said that to me the other day she said 'you've really grown since I've known you' and I said 'oh yeah' (laughter). (P344)

Being able to recognise this irony and find humour in it was a sign of how recovered she felt she was. Pettersen and Rosenvinge (2002) reported in their study of the patient's perspective of recovery from eating disorders that 'The desire for a better life was a general aspect of recovery' (p.65). This better life included 'continuing education, getting a stable job, or having a partner or children' (p.67). Woods (2004) in a study reporting untreated recovery from eating disorders reported that 'the need to experience and enjoy an authentic life is the most helpful factor in sustaining recovery' (p.366). Meanwhile Löwe et al (2001) reporting on a 21 year follow up of individuals with AN suggest that those who have 'a good eating disorder outcome were found to have a better living situation' (p.885). Thus, those individuals in work, in relationships and with children had less AN behaviours. The literature therefore offers support for the

benefits of engaging in activities outside of the AN in recovery. What these studies do not do is convey how they contribute to recovery. The participants in this study are suggesting that to replace the life they had with AN individuals must develop their relationships and occupational activities. If they do so then they become more aware of who they are and their value as a person.

Weaver et al. (2005) in a study entitled 'Understanding women's journey of recovery from AN' suggests a concept labelled 'replacing behaviours' which represent a different set of behaviours to those outlined above. These are behaviours not specifically related to AN but which are designed to bring about relief to the individual in the same way as their AN behaviours do. The authors list smoking, writing and suicide attempts as existing in this category with only writing seen as not dangerous to the woman's health. In this study participants describe replacing the limited and destructive life of AN with a different life of people and activities which help them to grow and make life more enjoyable. I will return to the Weaver study later in the thesis, as other aspects of it are relevant to the theory that emerged from the findings.

Once again, it is important to recognise the overlap that exists between the categories and their impact on each other. When individuals with AN pursue activities to support recovery they also experience the thoughts and behaviours of the illness. This is because the recovering process as seen by the participants was not linear and that change in one area could and

often did significantly affect other areas both directly and indirectly. An example would be where an individual starting to eat appropriate amounts of food. This would benefit them through improving their physical state and reduce hunger and preoccupation with food. This indirectly would provide more time and energy to engage in non AN behaviours which in turn would result in less time for the illness. A virtuous circle of continuing recovering was therefore likely. An alternative scenario is where individuals engaging behaviours outside the AN feel overwhelmed by the demands of the situation and copes by using the illness. This will reduce their confidence that they can recover and will result in a greater reluctance to try again. This staccato like movement in recovery with progress forward being accompanied by setbacks reflects accurately, how participants describe the process and highlight how complex and individual a process it is.

Getting and using support from others

The important role of other people in recovery is a central to the participants of this study and is present in most of the categories, which emerged. Much of the activity of recovering requires the individual to connect with others in a way that is more fulfilling and rewarding. This demands that they change how they have been interacting with others. In the sub category, *functionality of AN* we saw how for individuals with AN the illness offered a means of communicating emotional states to others whilst also reducing others' expectations. The literature has highlighted the reluctance of individuals to accept help (Palmer & Treasure 1999, Burkett & Hodgkin 1993). Combining the above we can see that to recover

individuals have to overcome significant barriers to accessing whatever help there is available. In a previous subcategory, *developing relationships with others*, I outlined some of ways in which participants received support from others particularly those closest to them. In this section, I want to deal with two factors those of, what determined whether such support was helpful or not and how professionals contributed to the process.

The first of these relates to how the involvement of others such as family and friends was judged to be beneficial or not. The two conditions were the closeness of the other to the individual and the knowledge of eating disorders the other had. In a previous quote, one participant noted that being too close to her mother contributed to her difficulties with AN and that she had to alter their relationship in order to recover. At the same time, she recognised how a certain level of closeness was valuable and helped her to recover. Other participants spoke of the closeness helping them to trust the individual and therefore being more willing to share with them and to believe what they said.

Ahmm...I would say people on the outside yes. For my family we have discussed an awful lot so they are very aware. I would say they are quite educated about it now because they have read a lot and I have let them read what I have written... I wanted them to understand weight was only a part of it and almost could be a trigger again'
(P349)

This is important in an illness where trusting others is difficult. Whilst others believed that those closest to them would be best able to tolerate

the strains the AN placed on the relationship. Lamoureux & Bottorff (2005) and Beresin et al. (1989) both describe the importance of trusting others in recovery from AN.

The second relates to knowledge of eating disorders and its affect on individuals. The more knowledge an individual had about the illness the more they were able to help in recovery. The participant above describes how she helped her family increase their knowledge of AN and that they found reading about it useful. Thus, parents and friends who understood more about the illness were more likely to be seen as helpful when compared to those who did not. However, only those who had experience of the disorder were seen as fully understanding what it was like and were therefore perceived as having more credibility than others.

'I don't think anyone unless you have had it will understand really what it takes to get over it...I think it is hard to explain what its like and I think its hard for anyone to ever know what its like. I think there are some out there who are more sympathetic than others but for most it's just black and white' (P346)

Thus others need both knowledge and understanding to be helpful and those who have had experience of AN and are recovering or recovered have a greater credibility when it comes to offering support.

A particular benefit of understanding the illness relates to recognising that it is not just about weight. This is important because of characteristics of

AN and the invisibility of mental work. The first discussed earlier is how the AN can function as a means of communicating distress to others. As the person recovers this means of communication is gradually eroded because their physical state no longer creates the impression of ill health and the need for support. A consequence of this can be that the 'others' become less concerned about them and reduce the support they offer. This can be devastating for the individual with AN for whom such a time is filled with uncertainties, risk and anxiety and they are more in need of support not less. Their fear that people would stop caring if they are no longer ill is coming true and they have yet no alternative way of asking for help.

As it is impossible to observe the mental effort and strain, the individual is under the work of recovery is 'hidden' from other people. If the 'others' do withdraw their support when there is physical improvement then relapse is more likely as the individual feels abandoned at a difficult time. If participants asked for help at this time and receive it from the right people then they will continue recovering. Equally, if the person close to the individual recognised the struggle despite the improved physical state and continued to offer support then this would support recovery. One participant at the end of her interview shared with me how her mother suggested writing a book about recovering from AN and calling it 'When all the flowers are gone'. The title eloquently conveys how important it is to continue to offer support when the obvious signs of illness are no longer present to demand concern.

Participants initially had little to say about the role of professionals in their care. However, as I have discussed within the reflexivity chapter this was likely to be due the demands of the context in which the research took place. As the contextual demands changed during the research the comments made by participants about the role of professionals also changed. Participants emphasised that the more knowledgeable the professional trying to help was about AN the more effective their help was likely to be. Participants reported that their recovering was at times hindered by their contact with professionals particularly if the focus was on weight and shape issues.

'I think that my idea of recovery might be different from a professionals idea and I imagine that, you know, measurements of BMI and weight and how its maintained would be an indicator to them of recover' (P349)

Here this participant describes how only after she had lost weight was she taken seriously.

Still I was fine because I wasn't underweight. In the end I did get underweight but that shouldn't have mattered the fact is I was bad when I was a normal weight, but the doctor didn't see the problem... they didn't take me seriously at all (P346)

The professionals' particular training was not seen as more important except in the context that medical staff had more power over individuals than other staff. This was particularly relevant in inpatient settings where

the medical professional was more likely to be associated with compulsory treatment. Recovering was supported by attention to these as well as other issues such as the individuals' relationships, mood, and building their lives. Participants did suggest that those who are specialists in the field might be different.

'The one I was put with to start with ... you had to tick suicide boxes about killing myself. You don't want someone just to talk to you, you need to be told what to do...then I had a social work lady... I don't think she had ever worked with anyone with this kind of illness. I've never actually spoken to anyone that's ever had it. The last two I saw, I had I found a lot more helpful, Louise and Emma, (Names have been changed) but I think they more kind of specialise in it' (P346)

However, within the literature there are other cautions for professionals. Malson and her colleagues (2004) employed discourse analysis to examine the construction of the 'eating disordered patient.' They found that when professionals constructed the individual as 'totally pathologised' (p.482) then it lead to depersonalisation of the individual and disempowerment. They suggested that there is no place left from which the individual, labelled 'anorexic can state her case about treatment and it be taken as valid' (p.482). They argue that professionals taking this position deny the individual the possibility of negotiating her treatment because 'she is a patient' (p.482). Given the importance of the individual feeling in control of the process of recovery discussed within the sub category re-

establishing control a relationship based on such power relations will not be helpful to recovery.

Not all of the participants had had inpatient treatment but those who did had mixed views about. It was helpful in that it provided a setting where the person with AN just got on with eating and restoring weight whilst receiving support from staff and fellow patients. It was helpful also to meet others who shared some of the experience of AN and *'It was nice to hear other people felt similar'* (P343). However, there were other aspects to inpatient treatment and contact with others with AN which were not helpful and could be dangerous. This participant describes becoming an inpatient was less difficult than being at home.

I was in there but it was quite comfortable to be there. It was more comfortable than being at home really because although you had choice, a lot of decisions were taken away from you... so being in the unit was easier in some respects (P342)

Another danger can be seen in participants reports of acquiring new behaviours when in contact with others and information about how to be better at AN. These iatrogenic effects have not received much notice in the literature (Rathner 1998) although Garner (1985) noted their existence and likely impact on individuals with both AN and Bulimia Nervosa. Individuals also described an urge to be the best at AN whilst as an inpatient although this was more manageable the less ill they were. Inpatient settings were also seen as untrusting and controlling environments with little room for

individuality. All of these characteristics are at odds with what the participants say is helpful in the longer term when it comes to recovering. This participant articulates the need for control mentioned in earlier section but adds that being seen as an individual and not just another patient or weight chart is important in treatment being successful.

Yeah, you have to feel in control. Because anorexia is so much about control that you have to.... for a lot of people... I don't know whether or not it is because they are so unwell physically that they have no choice or they are deemed mentally unstable , therefore they have no choice and they have to come here, and so its just regaining that control and independence for yourself and not just to feel like a patient or weight chart its to, its to be recognised as an individual you know just to, I don't know, to take control of the anorexia again is incredibly important. (P350)

Eivors (2003) in study of women's perceptions of their treatment stated that participants were concerned about the lack of negotiation and the feelings of powerlessness they experienced in treatment. Colton & Pistrang (2004) report similar findings in their study of women undergoing inpatient treatment and make suggestions as to how the centres could change to address them. They labelled the relevant themes for judging such centres in their study as, 'being with others; support vs. distress, 'being an individual or just another anorexic' and 'collaborating in treatment vs. being treated'. These themes echo what the participants in this study report. The

authors suggest that treatment be negotiated with individuals with AN and that it reflect their individual needs. A plea echoed by Kordy et al (2006).

Therapy, particularly one to one therapy was seen as assisting the individual to recover by helping them to understand both the AN and themselves.

Yes – I think that by going back into therapy – I've taken a step into recovery whereas before I didn't think about it, it was too far in the future and there was no time to think about it because of the food and eating.(P348)

Tozzi et al (2003) reported similar findings for therapy in their study of patients perceptions of what helped in recovering from AN. It could assist them to develop their relationships with others and provided guidance about 'getting a life', which was seen as very important. The type of therapy seemed less important than the relationship with the therapist and the knowledge and experience the therapist had. This is a finding replicated elsewhere in the literature on AN. (Lamoureux & Bottorff 2005, Maine 1985)

There is no clear evidence to recommend one form of treatment over another in the treatment of AN (NICE 2004). The aspects mentioned by participants, inexperienced or poorly informed professionals, limited collaboration between individuals with AN and the treatment team and too great a focus on weight as well as exposure to distressing circumstances

all contribute to a produce a negative experience. Whilst specialist knowledge, an understanding of AN, a collaborative approach to care and being listened to combine to produce the opposite. Studies such as those by Hsu & Holder (1985) and Sohlberg et al. (1989) looked at prognosis based on treatment response and treatment history respectively. They concluded that poor initial response to treatment and a longer treatment history were indicative of poorer outcomes longer term.

Perhaps rather than seeking prognostic factors in the presentation of individuals with AN we need to explore the treatment options we provide more closely for why they are not effective. What we term 'resistance' to treatment may be in some cases the only logical decision to take in light of its poor record in helping the individual to recover. Rathner (1998) in a chapter, which argues against compulsory treatment, suggests 'Moreover, dropping out from treatment with a therapist not experienced in eating disorders might be a wise choice' (p.191). Undoubtedly, some individuals will find treatment helpful whilst others will not. Professionals providing such treatment could utilise the guide provided by those with AN to ensure that all models of treatment do not make the task of recovery any more difficult than it is already. This will require a fundamental shift in how the therapeutic relationship is conceptualised within the bio-medical model

The individual with AN who engages in activities to combat the power of the AN, who takes on new roles and uses support from others will be able to tolerate life without the AN. In turn, this will support further recovery that

will develop their confidence in themselves. Treatment, especially one to one therapy is helpful, but it can also have iatrogenic effects, which have to be managed. In a way individuals are building a set of life experiences outside of those, they had within the illness. This life constructing work is another part of the individual's journey towards recovery. There is another important part that I have labelled *sustaining recovery* which is the final major category of this study.

Sustaining Recovery

Recovery from AN is difficult and hard work and this statement might appear superfluous. Indeed other authors confirm that it is hard work. (Stewart 2004, Hall 1993, Noordenbos 1991, Beresin et al. 1989, Maine 1985). The authors acknowledged that it requires effort to recover but as mentioned earlier ascribe this difficulty to the nature of AN and not to the process of recovery. All of the studies have in common the individuals with AN perspective on recovery from AN yet did not go on to elaborate the process of recovering or how it was to be sustained. Other studies reviewing outcome or recovery in AN do not acknowledge this difficulty. (Finfgeld 2002, Steinhausen 2002, Windauer et al. 1993, Lemberg & May 1991, Purgold 1987) Some more recent studies aimed specifically at the maintaining factors in AN (Schmidt & Treasure 2006) do elaborate the difficulties faced by the individual with AN. The authors ascribe these difficulties to personality characteristics such as perfectionism and coping strategies that are predominantly avoidant in nature. Thus, what might appear as an obvious observation is not much addressed in the literature.

In my clinical practice, I am aware of just how hard the recovering process is and that once engaged in it individuals are not guaranteed success. I distinguish between recovery and recovering to remain true to and to convey what the participants of this study said about the process. They describe recovery, as the destination they are aiming for, an event of the future to which they aspire. In contrast, recovering is the here and now and includes what they are doing to help them to get to the point of recovery. Sharkey-Orgero (1999) in a qualitative study of the perspectives of individuals recovered from AN and their parents on recovery found that 'Analysis of the data indicated that recovery is an ongoing phenomenon; therefore, *recovery* was changed to *recovering*'. (p.129, emphasis in the original). In this study, participants emphasised that the experience of recovering was predominantly one of a struggle and could undermine their desire to persist with the process. My assumption, linked to the normative view of recovering was that whatever it takes to recover is worth it.

In labelling this construct as I have, my aim was to stay true to the overall experience of recovering shared with me by the participants. They conveyed the necessity of the recovering process to me but also the potential for chaos and havoc that existed within it. They were clear that it was a difficult and scary prospect that they needed to undertake and the earlier subcategory *fears about recovery* discusses these. However, even more than this the participants were engaged in continuous version of the earlier main category of *deciding to recover*. In order for recovery to be successful, they had to attend to it and restate their commitment to it every

day. Without such a commitment, the risk of relapse was greater. The *sustaining of recovery* consisted of making the most of the *positive effects*, which serve to reinforce it, and being aware of and managing those events that undermine recovering.

Acknowledging the positive effects

Participants did not exclusively focus on how difficult recovering was. They acknowledged that happenings in the recovering process were also likely to reinforce further recovering. These included improvements in their physical health, the reduction of preoccupation with food and the greater freedom they experienced from the demands of the AN. They acknowledged the benefits of improved relationships with friends, families, and the possibility of greater potential in their future. They identified how recovering could benefit others who had supported them and this effect could reinforce recovering.

Yes definitely because although I'm doing it for myself essentially for my own health. Its also for at home – if I put on some weight seeing how happy my mum and dad are makes it seem extra worthwhile because I'm doing it for them as well – and my brother. They've all been so supportive and I think that after everything we've been through together it's nice to see them so happy. The smallest things say like putting on a pound, makes so much difference to them and definitely make it worthwhile. (P345)

For the purpose of clarity at this stage, I will separate them into these distinct conditions. First, the consequences of the work can produce effects which bolster wanting to recover. They do this by improving the life experience of the individual. When individuals have improved their nutritional state and restored some weight this would result in better concentration and more energy. It could also result in improved mood and less preoccupation with food. (Keys 1946). Similarly, individuals who have dealt with underlying issues such as a problematic relationship will experience an improvement in their mood and satisfaction with the relationship. The rewards for the individual are clear and lead to the recovering process being supported. Participants were eager to emphasise that psychological work without attention to physical issues would not result in recovery. They argued that the impacts of starvation were such that they either lacked the energy, concentration or capacity to deal with their AN without some improvement. They recognised that any psychological work would be less effective without such changes. Pike (1998) in her review of long-term outcome studies in AN supports this finding. However, such positive effects were not the only circumstances encountered by the individual whilst recovering

Managing the negative effects

Yes, and I think that's why I said that initially people just give up don't they; they can't cope with that constant having to fight. I can see and understand why they don't want to do it because the benefits don't come for a while either. (P351)

This participant conveys how the work of recovering made demands on individuals and could scupper the process. In the other three constructs of this study, the individual is required to engage in difficult activities if they are to recover. Without dealing with all of those particular aspects recovering will not occur. Once the recovering process is under way participants had to be very active and were required to attend to it minute by minute at least initially if it was to continue. Another participant marked the progress of their recovering by noticing the length of time that they had not thought about their AN on any one day.

Ahm and I just remember it taking a long time before I actually got to the point where "oh my goodness I didn't think about that for an hour or I didn't think about it for half an hour" ahm because you are scrutinising yourself so much you are so hard on yourself ahm on a day to day basis. P349

Earlier in the study I discussed the guilt experienced by individuals when they act outside the illness. The AN would in some ways 'fight back' making eating unpleasant or other AN behaviours appear preferable to how things were.

Obviously if you have a bad day you think "I'm back to square one" and so much ... even if you do something bad you think I've therefore blown it, I may as well not have bothered and sooooo... yeah I think all the negatives you think about yourself obviously make it harder

just still in the haze of that the depression of that, I was very very depressed (P350)

Individuals had to sustain their commitment to recovering by investing effort in dealing with the difficult and demanding work. This was in the context of their experience of recovering as unpleasant and feeling as though, it would be easier to be ill. If the demands of recovering became too great then a relapse was more likely as individuals sought a means of managing the overwhelming feelings experienced. This is not a perspective on recovering generally held. Usually recovery is seen as a positive endeavour with its own rewards built in. Participants reported that recovering could feel wrong to them in the sense that their life was becoming harder whilst recovering. They reported experiencing recovering as being like 'giving in' or failing particularly when it came to letting go of the control of their weight or taking on a new task. All of this contributes to the experience of recovering as a struggle requiring individuals to remove not only the symptoms of the illness but also to change their sense of self to which the AN has become attached.

Beresin et al. (1989) reported a similar finding in their study of individuals recovered from AN who described it as seeming like a 'defeat and betrayal of themselves' (p.124). It is important to note that Beresin et al's participants were those who had recovered and the authors suggested that those still ill would provide different answers. The participants in this study included both groups and reported similar experiences. The

significance for recovery from AN is that the individual with the disorder has to overcome this sense of recovering as being wrong for them to sustain their effort.

Sometimes participants found the emotional experiences of recovering overwhelming. Individuals recovering from AN found managing these experiences difficult or that the fear of hurting others prevented them from progressing with recovery. Although all participants agreed about physical improvement being necessary this did not equate to all being in favour of it happening. This does speak to some extent to the nature of AN and the denial of the illness reported in the literature. It also highlights again the interconnected nature of aspects of the recovering process. Recovery is experienced as unpredictable, there are no certainties with it, it requires risks to be taken and roles and tasks to be taken on for which individuals feel unprepared. All of these experiences challenge the motivation and commitment to recover and had to be dealt with or they would contribute to a relapse. Dealing with them meant applying specific skills, tolerating the emotions or calling on others, which in themselves are not easy tasks. Individuals draw on their reasons for recovering within the subcategory *making it personal* to continue the process in the face of these challenges.

Participants pointed out that in engaging in weight gain and giving up restricting their food they are acting in a manner at odds to the prevailing ideas within our society.

It doesn't help that there's all these things in the news about obesity and bad things and almost the entire rest of the population seems to be in this big thing about losing weight and you've got to keep your mind on basically doing the opposite or at least keeping things stable (P352)

Participants acknowledged that they needed to do this as discussed earlier however it is important to recognise the demands placed on them by continuing to do so in the context of cultural messages to the contrary. I challenge the reader to examine their instinctive reaction to the words, 'weight gain' and 'fat' to help explore this aspect of the recovering process. Usually the reaction to those words is universally negative because of the increasing stigma associated with them. Individuals with AN are just as attuned if not more so, to these underlying prejudices as we are. They must in the context of a diet-obsessed culture, engage in weight gain. Whereas before they received compliments for their discipline when losing weight, they must now forgo that if they want to recover and to use the participants' label to become 'fat'.

...at the same time the weight was dropping because I had to live up to this image of a stick thin pop idol sort of thing' (P347)

In western society, the preoccupation with appearance is well established and the pressure on individuals to appear in a certain way is culturally mediated (Gordon 2000). In recovering participants must not only challenge the *power of the AN* as outlined earlier but also these culturally

mediated standards of what is and is not acceptable. In restoring their physical health, they must achieve a stable weight at which they are able to function hormonally. The majority of women are now dissatisfied with their body shape so recovering requires the individual to seek out a body shape with which they are likely to be dissatisfied. The pressure to appear in a certain way is now being applied to men through the mass media and mediated by society.

Therefore, as individuals recover they are faced with circumstances and contexts to which they have to respond and decide to continue to recover or not. Participants experienced some of these events as dangerous because they had the potential to both support recovery but also to undermine it. One participant (P344) discussed it thus that when giving up the identity provided by the AN she did not know who she would be without it, did not know what others would expect of her and how she could cope with such expectations. The uncertainty, she contrasted with the certainty of her life with AN, which lead her to initially conclude that staying in AN was preferable to recovering. Yet the conclusion was not stable and is challenged by the impact of the disorder on physical health thereby increasing the motivation to recover. Individuals have to be vigilant throughout the process and do as this participant does.

Its a constant battle... its really choosing to do the harder thing why ... recovering you're constantly choosing to do the opposite thing to what's going on in your mind and you continue and so you decide to eat when you don't want to. That's going to change and create

conflict inside you which means your struggle is harder that day than if you just live with it and just decide to stop fighting and engage in the constant struggle and that's just the beginning of it and as you progress through the recovery it obviously ongoing as the challenges challenge your reasons why you got there in the first place (P351)

Individuals have to sustain their efforts in recovering particularly when the experience undermines their motivation to continue. They do this by acknowledging the positives of the process, remind themselves of the reasons why they want to recover and manage the events which they experience as urges to return to the AN. The context in which they do this is also important and is managed proactively by the individual.

Basic social process: The struggle to develop a more complex identity

I don't know who Louise (all names have been changed) is, I became so caught up in the illness I can't distinguish between me and the illness the illness is me as far as I'm concerned if I was to recover it would mean finding my own identity without the illness. (P343)

This quote captures how the AN has become associated with the persons sense of identity. The disorder defines the way the individual see themselves and determines how interactions with others and their environment are carried out. This individual is aware that recovering will

mean developing a new identity separate from the one provided by the AN. As they have, little idea of what their identity is without the disorder this contributes to their fears and anxieties about the recovery process. However, developing an identity is what is required to recover from AN. In this section, I will describe the struggle for a more complex identity as the basic social process in the participant's accounts. Whilst recovering the individual is doing more than getting better from AN they are developing new ways of being in the world.

Recovering from AN is a difficult process and requires that the individual make fundamental changes in all areas of their lives. It involves dealing with issues, which existed prior to the AN and which if not dealt with will lead to relapse. Recovering is a time of uncertainty for the individual and this can lead to progress towards recovery or away from recovery and into relapse. For the individual with AN a relapse into AN can be perceived as positive in the context of feeling overwhelmed by the demands of the recovering process. Whilst recovering individuals come to know more about themselves and the different capabilities they possess. Recovering activities have an interactive and cumulative effect on each other and on the individual's ability to sustain the process. It is therefore important to retain the holistic nature of the process and not to focus on just one aspect of it.

What emerges from the findings and discussion thus far is that the AN identity dominates the individuals life experience at the start of the

recovering process. Table 3.10, contains both the positive and negative characteristics of the AN identity which the participants of this study have highlighted and have been supported within the literature (Cockell et al 2002, Serpell et al 1999). The existence of these contrasting aspects of the identity contributes to recovering from AN being characterised as a struggle by the participants.

Table 3.10: The AN identity

Functional aspects	Limiting aspects
Safety Sense of control Less expectations Certainty/Rules Deal with difficult issues Elicit care from others Limits emotions Avoid fears	Isolation Obsession Physical ill health Loss of control Dependence Limits emotions Loss of potential

The AN identity is characterised by simplicity, certainty and a sense of safety. It functions for the individual through limiting emotional experience, reducing expectations from others as well as a means of dealing with difficult issues. It isolates the individual from other people, is destructive to their health and well-being and limits their potential to act in a different manner. This participant captures the impact of the disorder on her ability to relate to others.

Then I found I couldn't talk to anyone and then if I did I'd panic and have to be out the situation and make an excuse or you know... even

on the phone I'd say 'someone's at the door – got to go' – I just didn't want to talk to anyone because I felt like I didn't have anything to say of any relevance. All I was ever speaking about was myself and my body image and food and everything that went with that. (P347)

Thus, the AN identity is ultimately a stifling and limiting influence on an individuals' identity. The starting point for the process of change is when the individual becomes more aware of the aversive influence of the AN on their lives and concludes that the uncertainty and challenge of trying to be different, is the better option. If the individual does not reach this conclusion, they will not recognise the need to change. They will regard any attempts at helping them to change with scepticism and are likely to resist such efforts. Therefore, the first necessary condition is that the individual has to want to recover for her or himself.

In *deciding to recover* the individual considers the *limitations the AN* places on their existence and also their desire to be *more than* someone with AN. Their reflections illustrate to them both the costs and the benefits of living their lives as someone with AN. It is essential that they consider both, as any decision to recover taken without such consideration will be unsuccessful and short-lived. Often in a therapeutic setting the individual with AN is provided with information about the negatives of the AN whilst the positives are neglected or down played. A balance is required, where greater consideration is given to the downside of recovery. Through these steps, individuals become more aware of their identity as someone with AN

and what that involves. This participant summarises what is missing from her life with AN and the areas she needed to address in recovery.

When I started this whole thing and lost so much weight, I was really at that time in my life, I was really bored and lonely – I just had too much time to myself and I didn't have very much self confidence and my self esteem was really low and I didn't really have much sense of identity. I didn't really know where I was going with my life or what I wanted to do and I didn't really recognise any of my own good qualities as such. I just felt as if I was drifting. (P346)

However, as individuals start the process of change they begin to consider alternative ways of being in the world and the obstacles to achieving these. Individuals do this by reflecting on the dissatisfaction with the way things are and their desire for a better future. Other considerations include their fears about what the future may bring and whether they can cope with it. This allows the individual to imagine other ways they can live their lives that are not limited by the demands of the AN. The result of this is a contribution to their motivation for change and supports them in their deciding to recover the first necessary step to be taken.

In *deciding to recover*, the individual must ensure that the decision is personally meaningful and do this is by exploring their beliefs and values to decide which are important to them. This activity provides more information on which to base their desire to recover and ensures that recovery is for them and not for others. Recovery for others means a greater risk of

relapse in the face of the demands of the recovering process. This is because giving up the ways in which the AN identity is perceived as helpful such as providing a sense of safety, will undermine the motivation to recover. If the person is not doing it for himself or herself then their motivation may not prove sufficient to continue recovering. Others are important to recovering and the presence of emotionally close and knowledgeable others will help at this time to act as a guide and support to the recovering individual. Individuals may draw on the positive impact that getting better would have on others to help them sustain their recovery. There is one exception to the individual deciding to recover and this is where the individual is so ill with that others intervene to start treatment. In these circumstances, individuals may co-operate initially at the insistence of others. However, responsibility for their recovery has to be returned to them as soon as possible, if they are to continue the process beyond the crisis point.

When the individual identifies personally relevant beliefs and values these are often in conflict with those of the AN identity. Previously individuals only considered options available within the limited AN identity. If they did not they experienced guilt which would undermine their efforts to change. Now despite the guilt, behaviours motivated by their desire to recover based on their own beliefs have to be sustained. Thus socialising with others becomes a possibility when considered from the perspective of someone who is motivated to recover. The possibilities support individuals to build new representations of the self, which contrast with the limited

range available with the AN identity. The acquisition of knowledge about beliefs and values continues throughout the recovering process and contributes to further development and change in the individual's self-representations.

Therefore, in the activities of deciding to recover individuals take the first steps in developing a greater range of thought and behaviour than was available when ill. They do this through their, identification of why they are dissatisfied with the AN identity, consideration of possible ways of being that are outside of the AN identity and by clarifying what it is that is important in their lives. This knowledge guides them towards recovery and informs the plans they make to achieve it. Deciding to recover does not guarantee that recovery will happen as individuals struggle with giving up the AN identity. The struggle arises between the wish to retain the benefits of the AN and to let go of its detrimental effects. Individuals become aware that not having the symptoms of the disorder is only a part of their recovery and that taking on new roles, activities and tasks are necessary.

The other recovering activities are contained within the main constructs, *doing what is necessary* and *building a life without AN*. However, before proceeding to address the role these activities play in the development of the new identity there is another important aspect to highlight. Once the individual has taken the decision to recover, they must continue to do so to *sustain their recovery*. This is important because even though the individual has decided to recover they will continue to struggle with

overcoming the AN. The demands of the recovering process are significant, not only must the individual overcome a severe mental illness but they also have to change all the other areas of their lives to remove all trace of the AN. An example is the continued occurrence of AN thoughts after the decision to recover has been taken which is frustrating for individuals who want to recover and find such thoughts intrusive. If they perceive them, as part of what they have to tolerate to recover then they will continue to recover. Whereas if they perceive them as evidence that they cannot get well then they are likely to relapse.

Individuals with AN must restate their commitment because of other demands placed on them whilst recovering. These include circumstances, which the individual has previously avoided and which they must now face in order to continue to recover. Examples are traumatic memories or relationship difficulties with close others. Such circumstances arise throughout the process of recovery. Individuals have to *sustain their recovery* in the face of these challenges. They do this by drawing on personalised reasons for change, recollections of how destructive the AN is and aspirations for the future. They draw on the positives of overcoming the AN, which helps build their confidence. They use support from others to help them to continue to recover. The result of this effort is to reinforce new ways thinking and acting and builds confidence that they are able to live life without the AN. Having taken the risk to recover individuals are rewarded for their hard work. It also results in the individual acquiring further evidence of how they can be different. This combination of effects

creates a loop in which the individuals motivation to recover is sustained and their experience of life becomes broader because of their willingness to act outside of the limitations of the AN.

This concept of developing new ways of behaving rather than be limited by the demands of to the AN is also central to the construct of *doing what is necessary*. Individuals with AN must begin to repair the damage which the disorder has caused to their physical state. If they do not start to do this then efforts in other areas will be undermined. If they try to address psychological issues, they will not have the energy or concentration to do so. If they try to develop relationships or engage in occupational activities the demands of their starved state will prevent these being successful. To do this properly they have to improve their physical state and they do this through eating adequate amounts of food and limiting their activity levels. From the etic perspective these activities hold little fear but to individuals with AN they are filled with terror. They must choose to face this terror and tolerate the feelings that arise. They must resist the urge to manage such feelings and thoughts with other AN behaviours and discover new ways of managing them. In tolerating those aversive feelings and developing new ways of managing them individuals develop confidence that they can continue to recover, that they can tolerate life without the AN and acquire greater knowledge of themselves. All of these changes contribute to the development of a new identity separate from the AN.

There are certain conditions, which are applicable to addressing the physical aspect of recovering. A key one is that individuals in control of the physical aspects of recovering through having a say in the how and where are more successful than those who are denied this control. Some individuals prefer a residential setting whilst others prefer to remain at home or in the community. Previous experience of restoring weight can also be helpful unless it was a negative experience, which will undermine recovering. Individuals with AN must not restore weight too quickly or they will be overwhelmed by the changes to their body and will relapse. Nor should it happen too slowly as this will lead to frustration. Instead, the improvement in physical state needs to be synchronised with the other aspects of recovering which all combine to provide the skills to develop and then adapt to the new body shape and size. Just as with the other activities of recovering the individual is, when improving their physical state, expanding the possible ways in which they can interact with the world. The limitations of their emaciated state are replaced with the possibilities afforded by their improved state of health and greater energy levels. Such possibilities allow the individual to explore alternatives to AN and to call on their internal resources to help them manage the change.

Once Individuals with AN have addressed the initial crisis in their physical state, they must start to address the underlying issues that contributed to the AN. The improvement in their physical state will remove barriers to engaging in psychological work which served to maintain the AN. The nature of the issues will be individual to each person and require a solution

tailored to their needs. Issues such as, low self-esteem, childhood trauma, difficult interpersonal relationships and fears about maturation may need to be dealt with if they are relevant. If individuals do not address these issues then they will contribute to relapse just as they contributed to the emergence of the AN. Tackling these underlying issues helps the individual to learn more about themselves, to develop new skills in dealing with life, to let go of negative impacts on their lives and reduce the barriers, which existed to a more fulfilling life.

I also feel like I've got my personality back. I really lost who I was – my confidence.... I used to get on with all sorts of different people really well – old people, young people, kids anything – As useful or as worthy as.....I didn't have a personality or really think my life was of any useful purpose. Now because I've challenged stuff in my life I realise that it is and its only very very small – minute, in the grand scheme of things, but its something to other people and its something to me and its something I probably wouldn't have recognised if I hadn't gone through this. (P347)

When successfully completed this work leads to increased confidence that the individual can cope with life and addresses fears that they are not acceptable. In this study, most participants addressed these issues through engaging in therapy. It was most helpful when they determined when it took place and the professional providing the therapy was experienced in understanding the needs of those with AN. However, in a study by Woods (2004) looking at untreated recovery in eating disorders,

participants reported recovering without formal therapy and that relationships with close others was the key to recovery. The emergence of therapy as helpful for the participants of this study is likely to be due to the fact that all of the participants had undergone treatment.

Another way in which individuals manage the process of overcoming the AN and developing a more complex identity is to take responsibility for their recovery. In choosing to recover the development of personalised reasons for wanting to recover from AN creates a responsibility for all aspects of the recovery process. This is essential to the process being a success. Individuals must exercise control over the process in order that they can match recovery to their skills and ability to tolerate change. When ill with AN control is ceded to the illness, now they have to take it back and use it to assist recovery. If this does not happen or if others try to control recovery then the individual will resist change, experiencing it as imposed and contributing to a lack of autonomy. If control is wielded to support recovery then the individual will manage the process to reflect their needs and negotiate with others to support and help them. They will gain confidence from being responsible for their recovery in this way, as recovery will be down to them and not other people. The individual will get an increased sense of autonomy, of being in charge of their lives, which enhances belief in their ability to deal with further challenges in the recovering process. It also provides them with further experience of being a person who does more than just live their life as someone with AN.

As individuals continue to recover they acquire more evidence and experience of not being confined by the AN. The less time taken up with the illness the more space there is for individuals to build on their recovery and to explore other ways of being. They do this by taking on roles and activities neglected whilst they were ill. The first of these relates to relationships with others. Individuals who are ill with AN become progressively more isolated from others and closed off emotionally and socially due to the effects of starvation and the demands of the illness. To recover they have to rebuild relationships with others and start new ones. This participant speaks of how big a task there is ahead but that the only way to succeed is to push herself to be better in relationships with others.

I think it's the only way I can cope with it. Just to push myself and if I'm going to push myself to get over this illness which is going to be the biggest thing I'll ever have in my life, then I'm going to push myself to be more of a person and be more of a friend, and daughter and mother and you know – anything. I'm going to do the best that I can even better than I was before. (P349)

Components of this task include individuals renegotiating relationships with close others ensuring that they do not prioritise others needs over their own. They have to learn to communicate their needs as they relinquish the emaciated state that had previously communicated their distress to others. They have to acquire new ways of managing their fears that no one will care about them when they are well. They must learn to tolerate their anxieties and worries about not being acceptable, of not fitting in or of not

being good enough to deserve a life without AN. How they go about this will depend on their skills and abilities and the support network available to them.

Just as with previous aspects of recovering individuals are acting against the AN and more in line with their wish to be recovered. They are exploring alternative complex relationships in which they expose themselves more to others and run the risk of rejection. They are discovering that there is more to who they are and that people value them for that. Helpful ways of doing this outlined in the study are, individuals communicating their experience, sharing knowledge with family members and close others to help them to understand how best to offer support. They identified people whom they could trust and took responsibility for their needs and renegotiated the boundaries of relationships in line with those needs. They attended one to one therapy, family therapy and learned more about relationships through reading and their experiences. All of these activities help to develop self-knowledge and for individuals with AN such knowledge and experience contribute to their recovery and also to their development as a person.

Individuals with AN also have to take on new roles and responsibilities in the world of work or education. These recovering activities are another part of getting a life that has nothing to do with the illness and they are essential for a number of reasons. The most important initially is that they are distracting and take up the person's attention and time. This means that whilst individuals are occupied with the work or education they cannot

engage in AN behaviours. Work or study also provides positive feedback to the individual about their abilities particularly if it is personally meaningful to them. Paid work increases their independence and allows greater control of their environment. Work or study also provides the opportunity to meet new people and open up new avenues for social activities. If individuals take these opportunities then they are acting outside of the limits imposed by the AN and discovering how they manage in such an environment. They are also exploring other possible ways of seeing their 'self'. They acquire new roles, being a colleague, a student or a partner and knowledge that they have the skills and aptitude to be successful at them.

Alongside developing relationships and taking on new roles, I discussed earlier getting support from others as a means of tolerating the demands of life without AN. However, the role of treatment in the process of change is less clear-cut. It can contribute to creating a life without AN and professional help can be part of how that is achieved. However, individuals influence the success of treatment with AN and the professional offering the help. Deciding to accept help and co-operating with the treatment on offer are necessary for recovery to happen. Making the most of the treatment offered is also necessary because it requires that the individual work hard at it, if it is to succeed. However, treatment in its present format means exposure to others with the disorder. Such exposure to others can be helpful in that there is a sense of relief that the individual is not the only one and they can share experiences with others who are recovering.

Seeing individuals more ill than themselves can sometimes be a stark reminder of how badly AN can affect a person. This serves as a motivator to continue to recover and highlights the distance the person has progressed. However, it can also undermine recovery if the individual begins to feel competitive with others who are ill or learns new behaviours from them, which promote relapse. Resisting the urge to do so contributes to the individuals' sense that they can overcome the AN.

Looking at the personnel who provide treatment, professionals with a poor understanding or knowledge of AN or who lack appreciation of what is involved in recovering will hinder recovery. The specialist professional in eating disorders is more helpful because of their knowledge of AN but most valued is their awareness that it is about more than weight gain. Treatment that addresses the symptoms of the AN on the one hand and the personal development on the other is most helpful. Treatments which allow individuals to control the process as far as possible promote autonomy through ownership and responsibility for recovery. This increases the chances of success as well as the positive benefits to the individuals.

Earlier I mentioned the importance of keeping in mind the holistic nature of the recovering process. This is to reflect participants' view that the various aspects of recovering are connected and have an influence on each other. However, it is also important for the theory of developing a different identity than that which is associated with AN. From a chronological perspective, the first step is the decision to recover followed by steps to improve

physical health through eating and reducing over activity. These steps set up the possibility of further activities to achieve recovery. After this the next steps do not follow a particular order instead they reflect the individual circumstances of the person with AN. What is important is that each of the steps influences each other contributing to further recovery or not as the case may be. For example resisting the urge to over-exercise allows improvement in physical well being and gives confidence to the individual that they can continue to overcome the AN. The more recovering the individual has done the more confident they are that they can continue to recover.

Yeh – I found that the more I was on the path to recovery, the more I felt confident in talking to people or just being me (P347)

Another aspect of recovering relates to the uniqueness of the recovery journey for each person. How each individual manages the recovering process reflects their particular set of circumstances including how long they have had the illness, how it manifests itself, the skills the person has and the support network available to them including professional input. All individuals have to address the various demands of the recovering process such as repairing the damage and dealing with underlying issues but each individual deals with these demands differently. As this participant suggests the uniqueness of each person's journey is extremely important and that because of this standard approaches to treatment will be less successful.

So I think its incredibly important but I think that's why its so hard to treat as well because no two cases are the same, no one gets the same personal situation which causes their underlying themes and things you can identify but you cant ever treat two cases the same.

(P350)

When individuals with AN begin to change, they approach the other activities of recovering in a different manner than previously. The opportunities to react in a non-eating disordered way are increased. Because of this, they will experience themselves behaving differently than they would have whilst ill with AN. Either, these experiences help the individual continue with recovery or they undermine it. The first happens where the person can tolerate the uncertainties of the change process. Whereas the second occurs when they cannot do so and they relapse into the AN to help them cope. Individuals are building experiences of themselves as more than someone with AN. By responding to the challenges of having AN, deciding to recover from AN and then recovering from it they are developing a new and more complex identity than the one they had when ill with the AN.

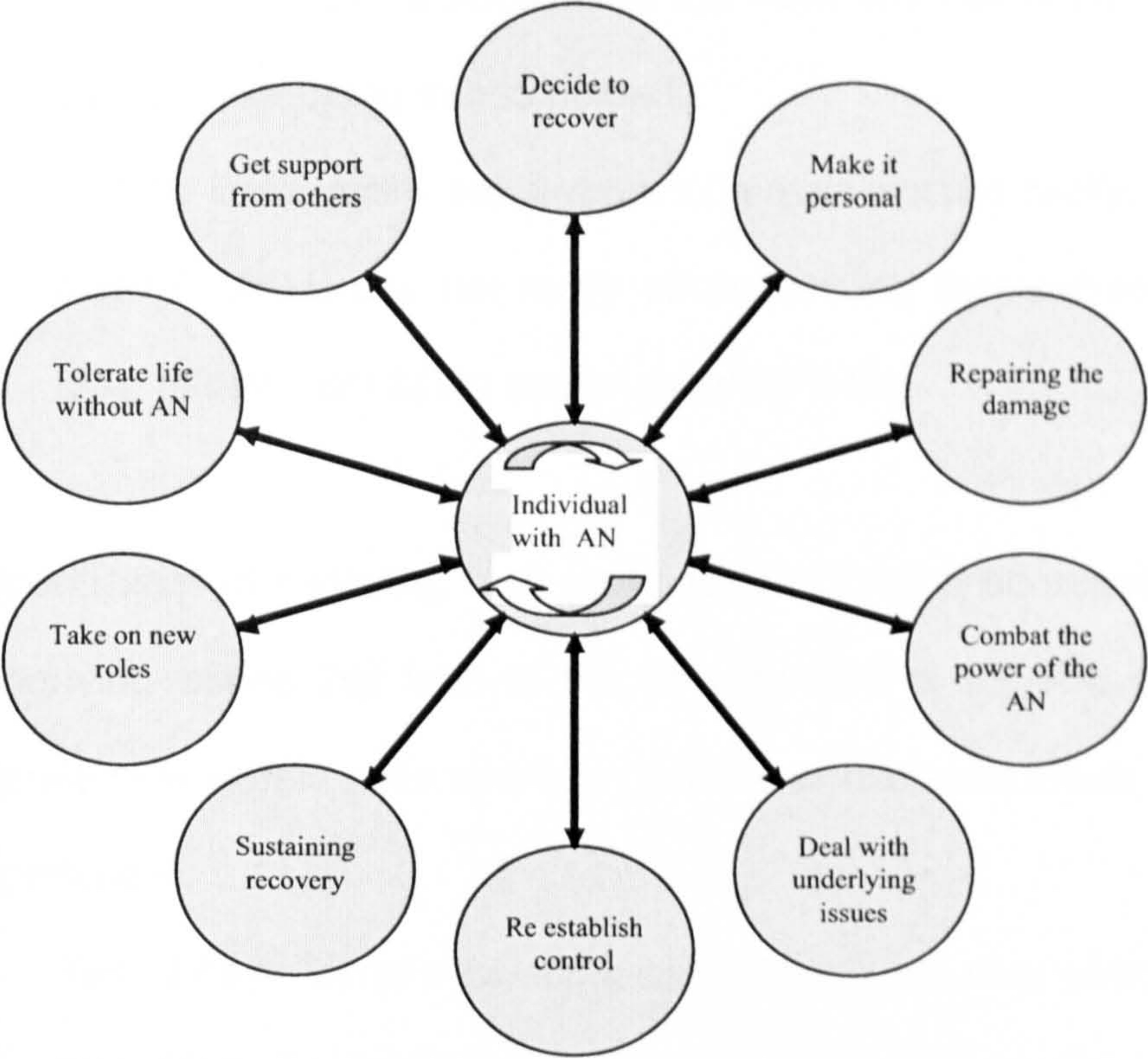
Figure 3.4 contains all of the main activities of recovering from AN, which have emerged from the study. This figure captures how the various aspects of the recovering process influence individuals with AN and each other thereby contributing to recovery. The central hub represents the individual with AN and the outer circles represent the activities they have to

engage in to recover. The individual has an executive function in that they must instigate actions in each of the outer circles and respond to their actions. This is conveyed by the arrows within the central circle depicting the activity of initiating and responding to changes. The feedback loop is a constant one from the individual to the outer activities and back to the individual. The arrows are bi-directional between the individual and the activities to convey this dynamic and that the influence on the process goes both ways. An example is when individuals start to eat an adequate diet, repairing the damage, this results in more energy for the individual. This energy can then provide momentum for progress in taking on new roles. The outcome here is towards recovery and the development of new ways of being in the world. The developments in the activity can have a positive or negative effect on the individual and hence on continuing with activities of recovery. An alternative is that the individual responds to eating more by becoming more anxious as a result of the underlying issues that are emerging and have to be dealt with. This contributes to an increase in the urge to restrict and the individual does so to control their distress. The outcome of this scenario is a return to AN.

The developments in the activity can have a positive or negative effect on the individual and hence on continuing with activities of recovery. An alternative is that the individual responds to eating more by becoming more anxious as a result of the underlying issues that are emerging and have to be dealt with. This contributes to an increase in the urge to restrict and the

individual does so to control their distress. The outcome of this scenario is a return to AN.

Figure 3.4: Diagram of Processes involved in developing a more complex identity.



However if the individual responds by sustaining their recovery then they progress towards a life without AN. The cumulative effect is that the individual develops a more complex array of behaviours and responses to their surroundings. The work of recovering means that the individual develops new ways of living their lives as well as giving up the AN. In turn, by virtue of the effort they put in and the experiences they gain, they are better able to continue recovering by drawing on these changes.

Having begun this section with a quote from a participant describing the need to develop an identity different from AN I will now return to the participant's words to help capture the impact of the work they undertake on their sense of themselves. First, for this participant the increased self-awareness, which arises because of the work she has done and how this contributes to her being true to herself.

I think it will make me a more complete person really. People go through day-to-day not really understanding themselves, and so at least I know I am being true to myself (P348)

Second, that of exploring their personal history and addressing whatever underlying issues that lead to the development of the AN, they have to tolerate new experiences and learn what their tolerance levels are for such experiences.

Yes. I have learnt a lot about myself and I am very positive and very motivated. But I do have my black moments, obviously. But I am also very aware of how I deal with things, and why this was caused in the first place. (P346)

Third, the individuals have to change how they were in the past and use the knowledge gained from their recovering activities to help keep it going. Reconnecting with others is vital to the recovering process because in isolation the AN grows.

To get an identity instead of being trapped in your own home or whatever. Isolating yourself – I think that's when anorexia breathes

and grows is when you isolate. To get out and to do things I think is very important. (P341)

Fourth, in keeping on recovering, the individual is choosing the tougher option and this makes them a stronger person more able to deal with whatever may happen in the future.

And, I mean, whatever happens at the end of this, I will come out a stronger person. I will know how I react to things and how I deal with certain things. (P349)

Fifth, because of how the individual comes to control their life in a healthier way leads to a feeling of empowerment. Another impact is the feeling that the individual can help others in recovering through sharing their experiences.

Sometimes I feel quite sort of – empowered. That I want to talk to people that are suffering now because I feel I have recovered. Like I say, I feel exactly.... And when I was ill I would never have imagined being like this. I did think it was going to be here for ever. I never felt I would change, when I was better – I felt I'd go back to where I was and you know, I feel empowered that, you can do this because if I can do it, anybody can. (P351)

This was not something the individual had imagined happening to them when they were ill. Instead, they felt they were going to be ill forever but now they had more options. Sixth, how the experience of recovering has

shown them how limited their identity was before and that they must now work very hard to retain what they have achieved

Yes definitely. I think now that I have to Because I was so unhappy, I have to give more and get more back to make up for the time when I was so bad. And because I don't want to go back to the person I used to be, I want to be better than that and be the best that I can be so I'm actually doing more and taking on more and being more of a person than I used to be before it happened. It's very weird – it's like being re-born (laughs) (P352)

Ultimately, how the process has changed them as a person and that the person they are now is preferable to the person they were when ill.

Yes – I recovered, but I didn't recover to the person I was before. I recovered to a different person, which is why, when we were saying this morning, would you want to go back – no I wouldn't because I was a different person before I was ill so if I went back I might go back to that person again. (P345)

Yet even that is not enough for the participant who describes how previously she was stuck and unable to progress further in her development as a person. However, recovering from AN has changed all of that, she is a different person but she also feels as though she is growing as a person all the time. Recovery for her has unlocked her potential to be different and to continue to develop as a person.

Yeh – I feel like a completely different person – that's the only way I can look at it really and I still feel like I'm changing now. Whereas when I was the person I was before I was ill, there was no change – that was just it. I never expected any change and it was just 'this is how you are'. Now I feel like I'm growing all the time. (P343)

Therefore recovering from AN involves individuals in the removal of the symptoms of AN but also replacement of the AN identity with a more complex identity that has more potential for growth. Table 3.11 lists the main aspects of this more complex identity which accompanies recovery from AN.

Table 3.11: Characteristics of the more complex identity

Functional aspects
Physical health Sense of control Empowered Strong Assertive Self aware Connected with others Continued growth Potential

The blank column under the limiting aspects of this identity reflects the absence of commentary on these by those who were recovered. For those still recovering there are fears about how they will cope, will they be acceptable or will others reject them when they recover. What the theory, which emerges from this study, suggests is that the further along the road

to recovery the individual is the more confidence they have and the more they are able to manage those fears. This comes about from their development of a greater array of behaviours and ways of being in the world than were previously available to them.

Identity in AN

AN has been characterised as a disorder of the self with authors proposing a causative function to such deficits. Bruch (1982) suggests that AN is caused by impairment in identity development and failing to develop many and different ways of self-definition. Bruch (1978) also suggested that eating disorders including AN may function as a maladaptive attempt to develop a self identity. Strober (1991) suggested that it is the personality variables of individuals who develop AN, such as high stimulus-avoidance and low novelty seeking that limit the exploration of alternative ways of being and therefore inhibit the development of more and diverse self representations. This view can be criticised as it struggles to explain those who have married, had children and jobs and then develop AN later in life. This may reflect Strober's background in working within a child and adolescent population. Wechselblatt et al. (2000) found that women with tendencies to be compliant and perfectionist are at greater risk of AN at times of developmental stress suggesting that their personality variables contributed to this vulnerability by limiting the development of a greater range of self-representations.

Other authors suggest that the difficulties with identity formation arise from parenting problems (Goodsitt 1997, Sands 1991). Piran (2001) and Malson (1999) suggest that society and culture contribute with pressures to develop in certain limited ways determined by the feminine ideal. This prohibits the acquisition of a richer more diverse set of identities and paradoxically promotes reliance on the feminine ideal to cope with the absence of an authentic self. This view contributes to an understanding of identity impairments for women with AN, still the vast majority of those with the illness, whilst neglecting the experience of men with disorder. Stein & Corte (2007) in looking at identity impairment in eating disorders note that, there is a general consensus within the literature that identity impairment has a role to play within eating disorders but that the specific nature of this 'has not been systematically addressed' (p.59). This consensus on the role of identity impairment in eating disorders including AN and the acknowledgement of the limiting effects of the AN identity on the individual, (Cockell et al. 2003, Tan et al. 2003, Serpell et al. 1999, Hornbacher 1999, Way 1993) lend support to the findings in this study relating to the limited nature of the AN identity.

Yet recovering from AN is difficult and demanding work. The etic perspective on such a limited existence would be that change would be welcome but for those with AN this is not always the case. In the introduction I discussed the concept of the 'egosyntonicity' of AN. Tan et al (2003) describes this as a phenomenon 'where the individual with AN experiences the AN as being a part of themselves or their identity' (p.537).

Surgenor et al. (2007) suggest that recovering activities in AN may be accompanied by an initial drop in self competence particularly if the individual has previously gained self esteem from the AN. Other authors (Surgenor et al. 2003, Serpell et al. 1999) have echoed the finding that the recipient does not always welcome improved eating disorder status. Tan et al. (2003) suggest that this sense of the AN having become a part of the person with the disorder, means that any 'decision to take up treatment can become heavily loaded with the implication of giving up a part of themselves' (p.546) The participants of this study also experienced recovering as aversive and described it as perilous. This sense of danger arose not only from the work of overcoming the mental illness, AN, but also to having to make changes in other areas of their lives. They had to develop an alternative set of ways of relating and being in their world and they were uncertain as to how they would deal with this.

Identity Formation

Stein and Corte note that problems with consistent definitions of the concept of identity hinder understanding and the progress of research (2007). I agree with identity defined as the theory the person holds about the self (Berzonsky 1992). Dunkel (2000) writes that this view treats the individual as an active participant in the construction of their identity or self-theory. The issue of identity formation, particularly in adolescents and young adults, has a distinguished history of theoretical modelling and is still being explored by researchers (Tan et al. 2003, p.537). Erikson (1968) made a major contribution to the development of self-identity by describing

a series of psychosocial stages through which the individual could pass as they developed their identity. Each stage posed its own particular dilemmas and difficulties for the individual and successful resolution saw the individual achieve a more complex identity. A key contribution of this work is that as Wilber (2000) puts it 'Instead of reducing all of life's problems to something that went wrong in the first age of a person, there are six or seven other ages, equally important, sometimes more important' (p.40). The implication was that it was no longer possible to reduce all of life's significant events to the early years of a person's life.

Marcia (1966) expanded Erikson's work and developed a model in which individuals could be classed 'on the extent of exploration and commitment they exhibit in life's domains such as occupation and ideology' (Dunkel 2000, p.519). Four classifications were possible. Those of the Identity Achiever, who had explored the options and were now committed to their choices; Identity Moratorium who are exploring their options but have not committed; Identity Foreclosure, who have committed without exploration and Identity Diffuser, who is neither exploring nor committed to any identity choices. Drawing on this model the AN identity is best situated in the Foreclosed Identity, classification as the individual is committed to it without exploring other alternatives. Recovering from AN would be placed in the moratorium classification as the individual begins to explore their options for the alternative selves they can be.

How does one move from one classification to the next? Berman et al (2001) state that 'Exploration is thus a process of examination and discovery of who and what one might be, with commitment to an identity being a consolidation of this process. As such, exploration might be seen as a basic process underlying the formation of identity' (p.513). Grotevant (1987) suggests a process model of identity formation and elaborates further on what exploration involves. He suggests that there are five processes that 'interact over time as the individual considers possibilities and moves towards making choices' (p.211). These are,

- Expectations and beliefs: where the individuals beliefs about the potential change and what possible options there are available.
- Exploration: This relates to the actual information gathering that the individual engages in and consists of both breadth and depth considerations.
- Investment: This relates to the amount of time energy and emotional investment the person makes. The greater this is the more likely the course of action will be continued. It is also likely to reduce explorative activities in other areas.
- Competing forces: Acknowledges there may be other events or choices in the individual's life that compete for their attention. In addition, there may be aspects of their lives they are not willing to give up for the new choices.
- Interim evaluation: This is an ongoing activity in which the individual evaluates the process, weighing the pros and cons and deciding to continue the path or not.

Table 3.12 reflects the positioning of these components of identity formation with the components of the theory of recovery from AN, which emerged for this study.

Table 3.12: Comparison of Grotevants components of identity formation with components of the theory of recovery from AN in this study

Identity exploration (From Grotevant 1987)	Recovery from AN
Expectations and beliefs	Deciding to recover/ Make it personal
Exploration	Deal with issues/ Take on new roles
Investment	Repair damage, Get support from others
Competing Forces	Combat the urge/ Tolerate life without AN
Interim Evaluation	Sustain recovery/ Make the hard choices

In *deciding to recover* individuals review their expectations and beliefs about the future option of not having AN and draw on the pros and cons of their present situation to help them decide about starting to recover. They reflect on their beliefs and value base to *make it personal* and ensure it is

something they want to do. They use their experiences from the past to decide if this option is one they wish to pursue. The conclusion that it is essential to beginning the process of recovery. After this, individuals engage in *doing the necessary tasks* and in *building a life without AN* and these activities equate to the stage of exploring. Individuals are actively trying out behaviours, which are not in keeping with the present AN identity. They are experimenting with different roles and activities and testing out possible selves. The greater the range of alternatives they try the more likely they are to find agreeable alternatives to the AN.

The investment individuals make in the recovering process is reflected not just in the initial decision to recover but also in their taking on new roles and acting in conflict with the AN identity. It is also evident in the effort required to *combat the power of the AN* and to *sustain the recovery*. In line with the prediction that the more time, energy and emotional resources committed to the process the more likely the process will continue, is the finding that the further along individuals are in recovery from AN the stronger and more confident they feel that they will recover.

The concept of competing forces is a key one for recovery from AN. As I have described in this thesis the AN identity comes to be valued by individuals and to recover they must let go of these functional aspects as well as those destructive ones so obvious to those without AN. Where AN has served to manage trauma, deal with difficult interpersonal relationships or an intrapersonal sense of being unworthy exploring alternatives will

inevitably lead to feelings of vulnerability and distress. These competing forces may derail individuals from further exploration of the new identity and lead to relapse into the AN. If this should happen individuals may recommit to the AN and cease exploring alternatives. Instead he or she may reinvest resources in defending the AN identity making further change more difficult. However, making such a decision is more appropriately placed within the concept of interim evaluation. Individuals review their decision to pursue the path of change on an ongoing basis and this resonates with the requirement to continue to recover from AN. When doing so individuals reflect on the pros and cons of their decision and proceed with, modify or stop the process depending on their conclusion.

There are some aspects of the theory of recovering from AN that have not been addressed by what I have described so far. These are the aversiveness of the process and the individual nature of the recovering task as described by the participants and covered in the literature. The concept of competing forces provides some explanation for such experiences in that giving up a personal identity the individual will also experience uncomfortable feelings. However, alongside this the individual would have to move into 'role confusion' (Erikson 1968) and here the individual must tolerate 'anxiety, struggle, and fluctuation without a settled sense of personal identity until the final (or alternative) identity status is found and established' (Tan et al. 2003, p.544). Individuals with AN may have developed the disorder to address low self esteem or to manage uncertainty in their life. In these circumstances, the reality of role confusion

would add to the demands on the individual and would be especially hard to tolerate. It would demand significant resources from the person to continue to recover which is how participants have described their experience of recovering.

The individual nature of the recovering process was emphasised by participants because of how it influenced the way in which recovering progressed. The response of the individual was determined by not only his or her own skill and resources but also those of the people in contact with them. Grotevant's (1987) process model includes a component labelled 'individual characteristic which he describes as, *'individual characteristic* includes abilities and orientations that individuals bring to bear on the identity formation process' (pp.204-205, emphasis in the original). Incorporating this concept recognises the influence the individual has on the identity formation both in terms of how these limit and expand the possibilities for the individual.

Another concept from the constructivist theories of identity formation that of 'possible selves' (Markus & Nurius 1986) is also helpful in this context. I unintentionally employed this term earlier in the thesis when discussing what an individual was doing when they were engaged in taking on new tasks. However, Markus & Nurius describe 'possible selves' as representing an 'individuals' ideas of what they might become, what they would like to become and what they are frightened of becoming' (p.954). They go on to state that possible selves are the 'cognitive components of

the hopes, fears, goals and threats, and they give the specific self-relevant form, meaning, organization, and direction to these dynamics' (p.954). The make up of the array of possible selves available to the individual will influence how they respond in different situations. These possible selves are hidden from others and provide a template for the individual to judge what is happening to them in the here and now. They can have positive selves and these foster hopes that change is possible from how the individual is now. Possible selves can also be negative and the effects and consequences of these can stifle change. An example would be where an individual with AN has a possible self of 'I am determined' they will react differently to an individual who has one which states 'I am a failure'. Although positive and negative selves are different in many ways they have one thing in common they 'make it difficult for the observer to fully understand another person's behaviour' (Markus & Nurius 1987, p.963). This characteristic is particularly applicable to AN as the disorder is very difficult for the outsider to comprehend. Stein & Corte conclude their study on identity impairment in eating disorders by suggesting that the 'development of new possible selves may be an important factor in recovery' (p.58)

Returning to the four classifications outlined by Marcia (1966) the person recovered from AN is within 'Achieved identity'. This is because, they no longer see the AN as their identity, they have through the recovering activities explored alternatives to the AN identity; they have invested time energy and emotional resources in pursuing alternatives to it and acquired

experience and knowledge of different possible selves. They have also experienced and tolerated the anxiety and uncertainties of giving up the old identity before the new one became established. Therefore, the exploration process has exposed them to other ways of being in the world and encouraged reconnection with others and their environment. They are no longer stifled by the AN identity but report a greater array of means of being in the world. They are committed to their new identity and demonstrate this through their drive to continue to invest in their recovery in terms of time, energy and resources. Table 3.13 lists the characteristics of this new identity.

Table 3.13: The recovered identity

Functional aspects
Physical health Sense of control Empowered Strong Assertive Self aware Connected with others Continued growth Potential

Therefore, recovered individuals have improved their physical health; they are connected with others, mindful of the needs of other as well as their own. They feel stronger as a person and empowered in who they are and their place in the world. They have engaged in new roles and taken

responsibility for meeting the expectations of those roles. They are proud of the ability to overcome the AN and now see themselves as more than someone with AN. All of this is in stark contrast to the stifled, limited and self-destructive existence they had whilst ill. The result for individuals of all their hard work and effort is a greater awareness of, who they are, their strengths and weaknesses and confidence to live their lives as they choose.

All of these changes are part of the more complex identity the individual recovered from AN possesses. The individual's identity or theory about the self contains a greater array of possible selves than when they were ill with AN.

A return to the literature

I began this study in September 2001 and I have revisited the literature from time to time to ensure that relevant articles are incorporated. Also as outlined in the introduction there were a small number of studies of the patient's perspective on recovery from AN (Hardin 2003b, Tozzi et al. 2003, Garrett 1997, Windauer 1993, Hsu et al. 1992, Beresin et al. 1989, Maine 1985) which I set aside to reduce possible contamination of the concepts emerging from participant's accounts. Two studies, Lamoureux & Bottorff (2005) and Weaver et al. (2005) employed a Grounded theory methodology to examine recovery from the perspective of the individual with AN. In this section, I will discuss the theory of recovery from AN, that of developing a more complex identity in relation to this part of the literature.

All of the studies were designed to access the individual with AN's perspective on recovery. The studies with the exceptions of Hardin (2003b) and Garrett (1997) reported on either turning points on the recovery journey or helpful aspects that contributed to recovery from this perspective. Tozzi et al. (2003) noted that the participants in their study endorsed 'relationships, therapy and maturation' (p.143) as the three main contributing factors to recovery. The finding that relationships are important in recovery is repeated in other studies (Windauer 1993, Hsu et al. 1992) however there is no attempt to describe why this might be the case. Beresin et al. (1989) describe how interpersonal relationships enabled the person to take risks with others and helped them to come to accept themselves, 'the good and the bad' (p.121). In this study, the renegotiation of and creation of new relationships provided valuable information about the individual's sense of self and self-worth outside of the AN. In this way, relationships contributed to the development of a more complex identity. This was achieved because the individual in exploring the new relationships acquired experience and knowledge of other selves they could utilise.

Across the studies, reference is made to the role of self-development in recovery from AN. Beresin et al. (1989) state that 'the process of recovering from anorexia nervosa is the process of becoming a real person' (p.127). They describe it as a slow process, which occurs only when the individual has a sense that 'someone is truly with them' (p.127) and this enables the person to 'unravel her maladaptive and self-

destructive defences' (p.127). The authors did not pursue the analysis beyond a descriptive stage but the similarities of the findings are supportive of those in this study. Hsu et al. (1992) in their study interviewed six individuals who had recovered from AN and asked them about what had helped and what had not in their recovery. Their participants endorsed the concepts of personality strength and self-confidence as important in recovering from AN. The authors did not develop these concepts beyond the descriptive stage, suggested that these terms would be difficult to quantify but that they would be a valuable part of future research into recovery from AN.

However, it is within the studies by Lamoureux & Bottorff (2005) and Weaver et al. (2005) that the finding about self-development in recovery emerges in a remarkably similar way to those, which emerged in this study. I will first describe their main findings and then discuss them in relation to the findings of this study. Weaver et al. (2005) employ a feminist grounded theory method and describe a theory of self-development moving from a stage of 'perilous self soothing' (ill with AN), through 'Finding Me' (Decide to recover) to 'Informed self care' (Recovered from AN) (p.191). I have included in brackets how the concepts relate to the stages of recovering. The authors describe the developmental process as running through three streams related to the self; those of self-awareness, self-differentiation and self-regulation. Through work in each of these activities the individual moves from the perilous self-soothing of AN to the informed self care of recovery. In 'finding me' which consists of a 'cognitive and affective

dawning that something is wrong', (p.195) the individual reaches a turning point in their illness and begins to recover.

Lamoureux & Bottorff (2005) employ a grounded theory method and describe their findings on the process of recovery as 'Becoming the real me'. This consists of five stages; seeing the dangers, inching away from anorexia, tolerating exposure without anorexia, gaining perspective by changing the anorexia mindset and discovering and claiming self as "good enough". The authors note that one of the difficulties of recovering was because the individuals 'sense of identity had become associated with AN' (p.182). Also that recovery involved embracing 'unconditional acceptance' and this was possible when 'the women had clarity of boundaries, identity, and self worth'

The similarities in the findings to those of this study are clear. Each of the processes refers to a turning point when the individual begins the recovering process, (Seeing the danger, finding me, Decide to recover). They also share the importance of the individual taking responsibility for their recovery, of reconnecting with others and the difficulty of the recovering process. Such a coalescence of findings around the concept of self-development is supportive of findings that incorporate redefinition of the self in recovery from AN. There are significant differences to how these similarities are theorised.

Lamoureux & Bottorff (2005) describe what the individual does to recover and refer to the similarity of the process to the work of 'identity development of Erikson' (p.184). However, they do not develop the analysis further remaining at the level of description rather than developing the links to identity formation further. Weaver et al. (2005) whilst emphasising the role of self-development suggest that the shift in self occurs when the individual recognises the dangers of AN and this facilitates the move to informed self care which in the model equates to being recovered. Given this both studies neglect the functionality of the AN as described in the literature and its role and impact in the recovery process. Although both studies acknowledge the difficulty of the recovering process, they do not develop the reasons for this and it is not apparent in the theory developed. This neglect of the experience of the nature of process is puzzling. The hard work and effort of the individuals who are recovering is not fully acknowledged nor is how it influences the process itself. The success experienced by participants of this study in resisting the AN is essential to their self-development and ultimate recovery from the disorder. Perhaps as Garrett (1997) suggests studies need to 'focus on the positive phase of an eating disorder; the process of its overcoming and eventual dissolution' (p.271)

Hardin (2003a) in contrast to the others moved the analysis into 'social and cultural discourses concerning recovery from anorexia nervosa' (p.5). She concluded that questions about recovery 'cannot be separated from social and cultural assumptions about, women, the body, weight, exercise and

how selves are constructed in western influenced cultures' (p.15). She is critical of attempts to do because they contribute to the lack of consensus in the research into this area and underestimates what is required to recover.

Only two participants referred to such cultural influences within this study. These were engaging in weight gain in a society obsessed with weight control or loss and the pressure to be thin when in certain occupational roles. All of the participants emphasised their role in the recovering process and their responsibility in ensuring it happened. Although they acknowledged the role of others in helping them, they were clear that they were the only ones who could make it happen. The participants may not have been aware of the societal influences on their views of their illness and recovering from it. Alternatively this finding could attest to the intensely personal nature of the recovering process for participants of this study and how they perceive it as a '*struggle with the self*'. Perhaps it is also a researcher effect, in that Hardin analysed her participants' views from the cultural perspective.

What emerges from this return to the literature is,

- Support for the concept of self development as the mechanism for change in recovery from AN and reference to the link with the work of identity formation
- Recognition of the difficulty of the recovering process but a relegation of this within the theory developed in terms of why it may be so difficult.

The theory of developing a more complex identity, which emerged from this study, captures all of these aspects through explaining the self-development through the mechanism of identity formation. The individual is engaged in developing a new identity and does so through rejecting the old one and exploring alternative ways of being other than those dictated by the AN. It captures the difficulty of the process because an individual in transition between identities experiences insecurity and negative affect associated with this stage of identity formation. Thus in equating recovery from AN with the formation of a more complex identity this would predict that the individual would engage in activities that lead to self development and would find this difficult and demanding.

Another area of the literature that contributes to the discussion of recovery from AN is the literature on recovery from mental illnesses other than eating disorders. Anthony (1993) remarking on the emergence of concepts of recovery in the literature, notes that 'it is most often found in the writings of consumers and survivor clients' (p.15). Ridgway (2001) ascribes the absence of the concept of recovery as possible for those with serious mental illnesses to 'the idea of recovery as heretical within the dominant biomedical model' (p.335). This she argues has had the effect of slowing the progress of research in this area. These observations echo the ones outlined in the introduction about the literature on recovery in AN and other eating disorders as described by Garrett (1997). In her study in recovery in AN she comments that the meaning of recovery as described by those

who have recovered is not taken seriously because of 'the unconscious power the medical model still exerts on the thinking of professionals' (p.271). The inference is that the concept of recovery has not only been neglected but the medical model has undermined its value to those with mental health problems. Table 3.13 contains a summary of themes, which emerge from the recovery literature in serious mental illness

Table 3.14: Themes in the recovery literature

Recovery literature (Adapted from Allott & Loganathan 2003.)
Reawakening of hope after despair Breakthrough denial to acceptance Withdrawal from to active engagement with others Passive adjustment to active coping Alienation to purpose Moving from a sense of oneself as mental patient to a more positive sense of self Recovery as a complex journey Recovery is accomplished with support from others. Recovery is more than not having the symptoms

The similarities with the findings of this study are clear from this table. The requirements to overcome denial, to be an active agent in recovery, to re-engage with others, to draw on support from others and to change ones sense of self are all present in the accounts of the participants of this study. Equally, that the process is a complex one is in keeping with the findings. One missing from this table but cited in Olson (2002) is the impact of those involved in delivering treatment on the recovery process. He remarks that his recovery journey has been made more difficult through not meeting someone who could 'throw off their diagnostic and treatment

blinkers, see my situation as it is and respond to me holistically' (p.442). This observation resonates with participants of this study's remarks on the need to see the AN as more than just about weight.

There are however some differences of note. The absence of the concept of hope from the findings of this study is surprising. Lamoureux & Bottorff (2005) and Weaver et al. (2005) also do not highlight the role of hope in their theories of recovery from AN. The literature cited earlier (Ridgway 2001, Garrett 1997, Anthony 1993) suggested that this could be due to absence of the concept of recovery from the medical model. Other studies in recovery in AN (Hsu et al. 1992 & Beresin et al. 1989) identify hope as important in the recovery process. Both of these studies specifically asked for participants views on what was helpful in recovery in contrast to this study which sought a description of recovering without an emphasis on what was specifically helpful or not. Thus, the participants were describing what it was like as they recovered rather than what their views were on what helped.

Participants in this study suggest that recovery means no longer having the AN as part of their identity whereas within the recovery literature in serious mental illness, absorbing the illness into ones' sense of identity is seen as part of the recovering process (Ridgway 2001). This difference reflects a distinction between AN and other illnesses outlined in the introduction, particularly its being of benefit to the individual. The fact that AN comes to be perceived as part of the self implies that recovery from it will mean it

can no longer remain so because of its destructive impacts. The conclusion is that some of the work of recovery in AN will be different from in other serious mental illnesses.

Chapter 4: Conclusion and Implications

Theory of recovery from AN.

The four main dimensions and the tasks associated with them are listed in table 3.15

Table 3.15: Four main dimensions of recovery and their tasks

Dimension	Tasks
Deciding to recover	<ol style="list-style-type: none">1. Recognising the limitations of AN2. Acknowledging the benefits of AN to them3. Wanting to be more4. Fears about recovery5. Make it personal
Sustaining recovering	<ol style="list-style-type: none">1. Acknowledging the positives2. Managing the negatives3. Deciding to recover
Doing what is necessary	<ol style="list-style-type: none">1. Repairing the damage2. Dealing with underlying issues3. Re establishing control.4. Combating the power of AN
Building a life without AN	<ol style="list-style-type: none">1. Taking on new roles2. Getting support from others

Recovery for the person involves the successful integration of the four major dimensions of recovery; *deciding to recover*, *sustaining recovering*, *doing what is necessary* and *building a life without AN*. Each of these dimensions represents a series of tasks, which the person must complete,

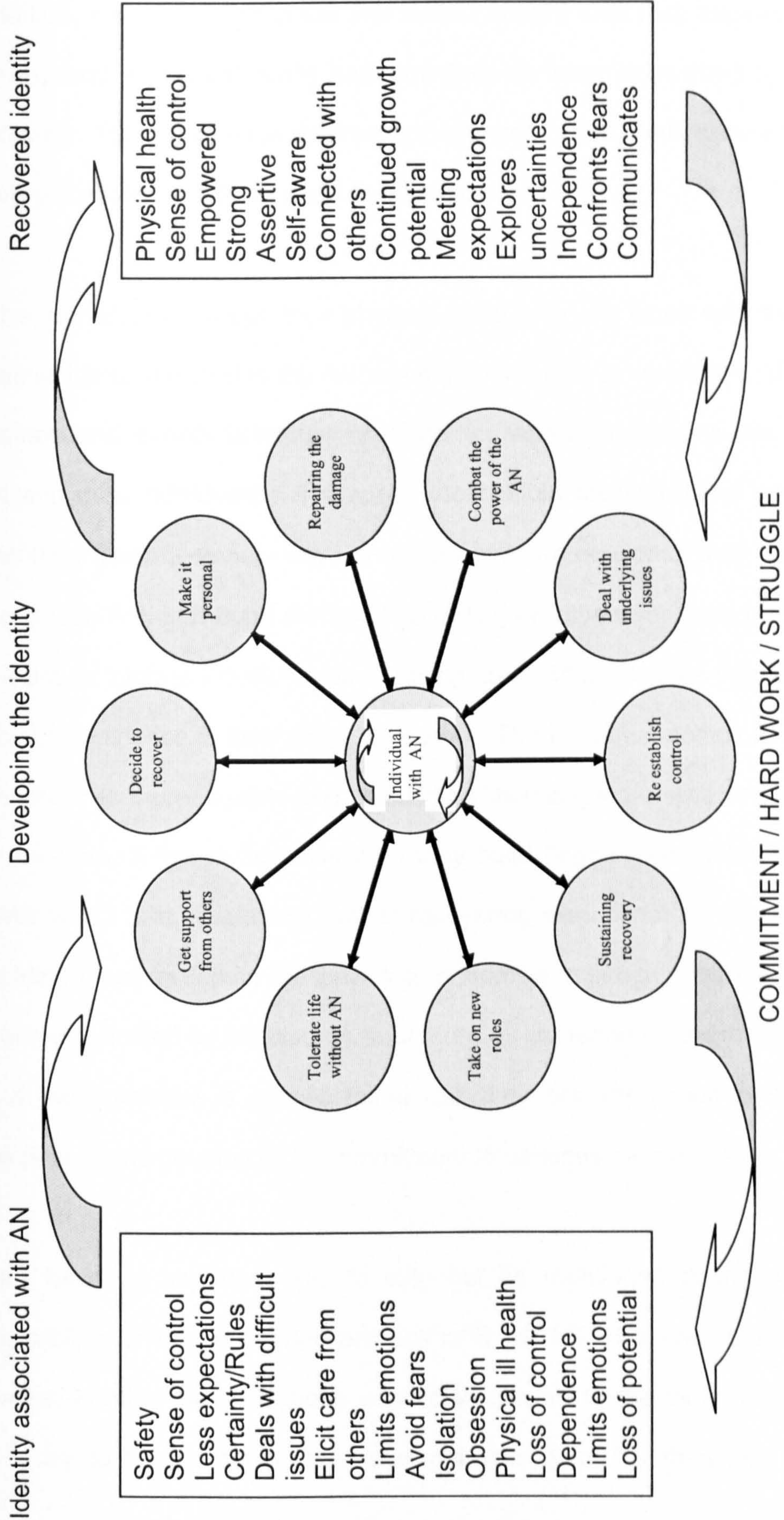
to varying degrees, if they are to recover. The person must distinguish between recovery, the end point of the process and recovering which contains the work of integrating the four dimensions. Integrating the four dimensions is a spiralling process where the change in one depends on and is influenced by change in the others. If the configuration of the four dimensions is favourable towards recovery then recovery will be supported, if it is towards relapse then relapse will occur. Recovery is meaningful and is established when the person develops a more complex identity. If the individual fails to do so, they will remain vulnerable to relapse. If they engage with the difficult and demanding work of doing what is necessary and building a life outside of the AN then they will create and experience new ways of being in the world. It is in the courageous work of the struggle to recover that the new more complex identity is forged. In tolerating the demands of these difficult tasks the individual is transformed into a stronger person, reconnected with others and in control of their lives. What follows is a description of the conditions which apply to the process of recovering from AN which emerged from the study.

Individuals with AN have their identity limited by the illness. The characteristics of the AN identity can be seen on the left hand side of figure 3.10 on page 210. When individuals decide to recover, they begin the process of developing a more complex identity. When the individual examines the limitations and costs of the AN and recovery from it, they increase self-knowledge then become aware of other possible ways of living outside of the disorder. Once the balance of costs and benefits is in favour of recovery individuals want to recover more than they do not. If the

individual makes the decision personally meaningful and takes responsibility for the recovering process it will continue. The exception is where they are so ill that others take the decision away from them and they are treated against their will. However if individuals allow others to remain responsible for recovery then they are likely to resist recovering and relapse because of the lack of sense of control they have.

An effect of the process of recovering is when the individual becomes more aware of their motivations for a life outside AN they imagine themselves as being different from how they are now. The individual then engages in the rehearsal of possible alternative selves, which can replace the AN identity. Individuals use their desire to be different and invest effort in making it happen which provides the energy to drive the process of identity change. Others, such as friends, family and professionals can help reduce the symptoms but no development of identity will take place without the individual. Once having decided to recover the individual has to tackle the necessary tasks. If these tasks are avoided then recovery will not progress beyond the wish to do so and the individual will become frustrated. They must begin to behave differently, i.e. eat and thus tackle their physical state. If the damage the illness has caused is not repaired then the individual will not have the capacity to sustain the process of recovery. This is because of their starved state and its impact on cognitive functioning and physical stamina both of which are essential to sustain the process. Figure 4.1 is a more detailed summary of the theory.

Figure 4.1: Theory of recovering from AN; Developing a more complex identity



In addition, if they do start to eat and restore weight then they experience behaving and feeling differently from how they do when dominated by the AN identity. Tolerating these different experiences builds confidence about recovery not tolerating them leads to relapse.

As the individual improves their physical state they are faced with those issues which contributed to the AN and may now serve to maintain it. If the situations and events previously avoided for whatever reasons are not dealt with then individuals will relapse. Successfully tackling these issues opens the individual to new ways of being which are outside of their range when ill with AN. If through therapy and calling on others for support they can learn to tolerate the demands of facing such difficult issues then they will build confidence in their ability to recover. The individual comes to see themselves as more capable and as building knowledge and awareness of who they are. If this is the case then they build ongoing commitment to recover which in turn supports further recovering work. Another outcome, of tackling these issues for the individual is, coming to see themselves less as someone limited by the disorder and more as someone recovering from AN. If the individual is successful at this they become proud of their achievement and develop more commitment to continue the process.

Others have an important role to play but as mentioned cannot take responsibility for the recovering process or it will fail. However, they are important in other ways. If those who offer support to the individual are both close to the individual and knowledgeable about AN then they are

more effective at helping than others who hold only one of these characteristics. An important aspect of this is that the understanding that improvement in physical status does not mean that individuals with AN are less distressed. If those who offer care and support think like this and reduce the support offered then individuals with AN feel abandoned with the result that the risk of relapse increases. Similar conditions hold true for professionals who are trying to help. If the professional demonstrates understanding of the disorder and skills in supporting those with AN then any interventions are more effective. If they focus too closely on weight and neglect the other issues then they are less effective and may cause harm. The individual with AN must control the process of recovery. If anyone else tries to make him or her recover, it will fail because ultimately no one can force recovery on another against their will. The individual's sense of autonomy which has resided in the AN must now be reclaimed. A consequence of choosing to start and then persist with recovery is that the individual comes to feel empowered. It is from the commitment and effort required that a sense of control and power over life emerges and leads to an increased sense of autonomy. Without this sense of autonomy and control of their life the individual will relapse into AN to find the control they need.

All of the above is essential because of the need to integrate the four main dimensions of recovery. The direction of change in one depends on and influences change in the others. Therefore, if the progress is towards developing a more complex identity then recovery will be supported.

However, if progress is away from a change in identity then the risk of relapse is greater. An example would be if individuals have not begun to repair the damage caused by the illness then they are not going to have the energy to continue to recover. Thus for individuals to continue the process by taking on new roles they must have begun work in at least one other area. If they do start to take on new roles in life then they will react in two ways. If such change cannot be tolerated or the fear of rejection by others comes to dominate the individual then they will be more likely to relapse. If it can be tolerated and positive feedback received from others then they will continue to recover. Further exploration of new ways of being in the world and responding to it are possible as someone recovering from AN. This requires the renegotiation of relationships a striving to connect with people as opposed to the isolation which is part of being ill. Without such exploration no challenge to the negative beliefs held about themselves is possible because no evidence is gathered to contradict them. Individuals must take on or retake roles in their lives neglected when they were ill and meet others expectations in those roles. Taking these roles and tolerating the demands of this change leads to the development of new representations of themselves and helps build confidence in their ability to recover.

In developing a more complex identity individuals with AN have to re-engage with the world of work and/or education. Opportunities for distraction from the AN are sought which provide respite from the power of the AN and builds confidence in their ability to recover. There are other

benefits from the financial and social opportunities offered by the worlds of work and education. The more personally meaningful these opportunities the more helpful to the aim of recovery. If the individual cannot find these new roles, or tolerate the demands made they relapse into AN or adopt other unhealthy coping mechanisms such as alcohol or drug use. When individuals use the new representations of themselves generated by this work to replace the AN identity then they recover.

The essence of the theory is that individuals with AN have a limited sense of identity when ill. This identity has both functional and dysfunctional aspects to it, which make changes to it difficult and demanding. However, if the individual does not take steps to move away from the limited identity associated with AN they will not recover. Not being able to tolerate the change associated with these steps leads to any recovery being fragile and the risk of relapse very high. If however, the individual explores different ways of being in the world and takes responsibility for building a life without AN then they build knowledge of and confidence in their ability to recover. Recovery is difficult and demanding. Individuals must invest sufficient effort in the struggle and become committed to the process. The more committed the individual is to recovering the more successful they will be in managing the process of integrating the four main dimensions of recovering. The result of this work is that individuals in sustaining the effort, will be exposed to a process, which alters them as a person and when complete creates a new identity. The limited, isolated and self-destructive identity of AN is replaced with a more complex identity which promotes connection with

others, personal empowerment and the facility to continue to grow as a person.

Recovery from AN is a struggle with the self and it requires that individuals engage in courageous work to overcome the devastating effects AN has on their lives. The illness comes to be experienced as part of the individual's identity and to recover this has to change. Unlike other identity development, it is not a naturally occurring process rather the individual has to instigate and then maintain the process. The first step on this road is when the individual decides to recover. This involves reflection on the destructive impact of the disorder on their life and that of others and from this emerges a desire to change. Acknowledging the benefits of the disorder reduces this desire as does the individuals fears about how they will cope without the AN. Without consideration of these aspects of recovery, the individual's motivation will not be sufficient to withstand the demands of the process. It is also essential to allow individuals to take responsibility for his or her recovery. The knowledge gained from engaging in the reflections helps guide the individual as to what they must do to recover and to be better prepared for its demands. Individuals through their reflections are considering other ways of being in the world outside of the limited repertoire available to someone with AN. This new array of thinking and behaving then serve as a template for how they manage the next steps in the recovering process.

However, the AN remains as one of the possible identities they can choose so the individual must sustain the decision to recover. The attraction of the

AN identity with its certainties and security is made greater because in the transition between identities, the person encounters a period of anxiety and uncertainty which is likely to be aversive. Individuals must therefore invest resources in sustaining their recovery. These include time as well as physical and emotional energy aimed at dealing with the demands of the recovering process. In addition, in the transition phase the individual must begin to deal with the damage caused by the AN and the issues, which contributed to its development. In doing so, they are actively exploring alternatives to the AN many of which are in conflict with the AN identity. They must tolerate this and if they do, they will increase their repertoire of possible ways of dealing with future demands. They gain confidence from this success and the increased self-knowledge that it brings which in turn positively influences their desire to recover. The more resources applied to the process the more committed they become to recovering and the greater the changes they will make.

In line with this, the individual with AN must now expand their efforts at recovering to include reconnection with others through relationships and beginning to take on new roles. In the former, individuals must renegotiate old relationships to reflect their new identity particularly in recognising their own needs alongside those of others. It also involves the development of new relationships, which are based on new ways of relating to others outside of the limited ways available as someone with AN. The input of others is very important to the recovering process in terms of the support they provide and the opportunity to provide feedback to the individual

about their new ways of interacting. Professionals also can play a role in providing specialist input and providing psychotherapy, which assists the individual to deal with issues and acquire more self-knowledge. In the former, the individual is also exploring new ways of being. They take on jobs, education or return to old roles whilst accepting the responsibilities that they bring as opposed to avoiding them as they did within the AN identity.

In recovering individuals must challenge themselves to respond in ways different to those dictated by the AN identity and more in keeping with the more complex identity they are developing. The individual engages in regular reviews of how their recovery is progressing. Initially very frequently and maybe even daily or hourly as the individual struggles with the demands of the process. The outcome cannot be taken for granted particularly if the demands of the recovering process overwhelm the individual's available resources. In this case recovering will be abandoned for the lure of the AN or an alternative means of coping with the situation. Therefore relapse into the AN remains a possibility until the individual has committed fully to the new identity and describes themselves as recovered.

However as recovering continues the reviews become less frequent as the individual becomes more comfortable with their change in identity. The individuals success in their new roles and the benefits of their new relationships provide confidence that they can tolerate life without AN. They describe themselves more in terms of who they are rather than in

relation to the AN. Individuals develop greater self-awareness, recognise their strengths, and do not focus only on their weaknesses. The recognition of the transformation in their identity contributes to a pride in their achievement in recovering. They are confident that what they have learned about themselves and others will help them deal with difficult issues in the future. Some individuals demonstrate their newfound confidence by offering to help others to recover just as they have done. When this point is reached the new identity is well established and the individual no longer see the AN as part of their identity and describe themselves as recovered.

Implications

Contribution to knowledge

This study contributes to knowledge in two ways, supporting previous findings on recovery from AN and adding new insights which have implications for how recovery is perceived.

It supports previous findings of,

- a) The existence of functional as well as destructive aspects of AN
- b) The role of self-development in recovery from AN
- c) The difficult nature of the process of recovery from AN from the perspective of the individual with AN.
- d) The importance of the individual with AN being responsible for his or her own recovery.

It adds to the literature,

- 1) That the formation of an identity different to that of someone with AN is a central task of recovering from AN.

2) Further understanding of the demanding nature and difficulties in recovery from AN from the perspective of those who undergo it. This contribution comes from the insight of the individual entering role-confusion in the transition from the AN identity to a more complex one, a time of insecurity and anxiety.

Taking what the study adds as a starting point, there are many implications for those who are involved with individuals with AN. Given that self-development is a frequently reported finding and that the creation of a more complex identity emerged as central to recovery in this study, greater attention should be given to interventions that can support such self-development. Treatment models, which rely too heavily on a focus on physical symptoms, will be unsuccessful at promoting recovery and are likely to contribute to relapse. Professionals will need to continue to provide interventions to address physical needs but should promote models of care that give equal weight to the self development work. There should also be more efforts aimed at assessing identity, particularly on presentation to services to guide further intervention. By necessity, this implies greater understanding of and training in available methods for doing so such as art and drama therapies.

As outlined in the introduction of the theses the focus on a limited set of measures of outcome does not capture the complexity of the process of recovering from AN. The increasing tendency for resources in mental health care to be linked to outcomes presently measured as important

highlights the dangers of not measuring outcomes more appropriately. A specific risk given is that the limited nature of outcomes measured at present will hamper the development of more appropriate measures and stifle progress towards more effective models of intervention. The findings in this study suggest that it is important to employ a broader approach to the measurement of outcome to embrace qualitative and quantitative methods in order to capture more fully the impact of any intervention. However it also implies that a greater weight be given to the individual with AN's perspective on how they are recovering and not just be focussed on their satisfaction with treatment received.

The difficulty of the recovering process is a common theme within the literature reporting on the experiences of those who have experience of AN but is dismissed more lightly by the professional literature. The finding in this study of the difficult nature of recovering allied to participants reporting that discussing recovery was a novel topic merely adds further support to such a position. The result of this for the participants is that they believe professionals confuse treatment with recovery and do not give enough recognition to the difficulties the individual faces when recovering. For professionals, a lack of appreciation as to what recovery involves may unintentionally promote prejudices about 'resistant anorexic patients who reject treatment' with detrimental effects on the therapeutic relationship. Being treated as an 'anorexic' was universally experienced as aversive and likely to lead to a withdrawal from treatment. It may also mean that they underestimate the effort taken to recover and offer adequate support when

the individual is recovering at a time of more need not less. The findings of this study imply that the accepted prejudices that exist in the professional lexicon in the treatment of AN need to be revised in the light of this finding in particular. Given the suggestion by participants that those staff with a specialist knowledge and understanding were most helpful to them, additional knowledge and information about recovery would add to both. Such information could more credibly be shared by those who have had experience of recovering from AN as long as they were appropriately rewarded for it. This would also be helpful to those who care for someone with AN. A shift to a perception of the individual with AN as engaged in courageous work would more accurately reflect what emerges from this study.

This study provides insights into the process of recovery from AN, from the perspective of those who have experience of the disorder. Aspects of this perspective challenge the normative view of recovery present in the medical model and as such have implications for models of treatment predicated on such a model. The central role of the individual with AN to the success of recovery requires that professionals delegate greater responsibility to the individual in deciding how to proceed with any treatment. The professional has to cede that the individual is an expert in their situation and acknowledge that because of this the individual will be the best guide as to what happens next in recovery. The main advantage to this is in the sense of ownership the individual has which is essential to a successful recovery. It will also avoid the battle for control, which

participants reported as occurring between them selves and professionals. Both of these outcomes will assist the individual with AN to develop their sense of autonomy a key component of their new sense of self.

There are also implications for the carers of those with AN and guidance on how best to help. The finding that those closest to the individual can both hinder and help is not new but the suggestion that the more knowledge they have about AN does help is significant. The natural instinct to become less concerned as the individual starts to restore weight has to be resisted as for the individual with AN this is a more uncertain and unsafe time. The individual needs more input not less at this time. Such information needs to be made available in an easily accessible form to carers so that it can inform their caring. Janet Treasure and her colleagues in London have over recent years been developing just such carer skills training and have been employing carers alongside professionals to deliver this. The imperative of having sufficient knowledge of the disorder holds true for the professional as well as those without professional healthcare related training. The implication is therefore that whoever delivers interventions to individuals with AN will do it more effectively the more knowledgeable they are about the disorder and how it affects the individual. A better understanding of what recovering from AN is like and what it takes to be successful at it are also important skills to be available to the professional. Developing training modules to deliver these skills to the professional should draw on the experience of those with AN, professionals with experience in the field and lay carers. These training

modules should also place greater emphasis on an agenda of social inclusion particularly educational and occupational opportunities for those with AN.

The finding that the first step in the recovering process is the decision to recover implies that interventions could be fruitfully aimed at helping the individual reach this conclusion. Support to reflect on the pros and cons of the AN already occurs within treatments designed around the transtheoretical theory of change (Prochaska et al. 1992). What this study adds to this is that attention should also be paid to the individual's fears and hopes about recovery and the recovery process. Identification of obstacles to recovery by the individual would provide guidance as to how they could be overcome and to which interventions would be helpful in them doing so.

This also implies that the individual undertake more preparation for the recovery process in order to increase their chances of overcoming the obstacles to it. This by necessity means that they should be provided with accurate information about recovery and outcome in AN. A problem with this, as outlined in the introduction is that the data we have on recovery suggests low rates of recovery and is unlikely to engender hope. Although not a finding in this study, hope has been found to be essential in recovery from other serious mental illnesses and in other studies in AN. One method implied by this study is to draw on the experience and knowledge of those who have recovered from AN. For present service models, this would require considerable thought as to how this could be arranged and how the

individual could be rewarded for their input. Within the local service we employ an individual who is recovered from AN through a voluntary sector organisation to contribute to the therapeutic programme we provide. The small bureaucratic burden to this is more than offset by the credibility given to this individual by others in treatment for AN.

Suggestions for further research relate specifically to ways in which further information could be gathered about the role of identity formation in recovery from AN. This may be particularly relevant in the context of the concept of early intervention which has become established within the treatment models for psychosis. Research looking at the impact of early intervention strategies particularly in preventing the AN identity taking hold could provide beneficial information. Research into the range and types of possible selves present in those with AN and those who are recovered would provide insight into changes in these mechanisms of identity formation. Assessment of possible selves as an adjunct to treatment trials could also provide information as to interventions, which promoted one of the means of self-development.

There should be more qualitative research into the process of recovery and outcomes. This research would add complexity to the bones of the quantitative measure already available and provide more detail for the individual with AN, the carer, the professional and the commissioner of services to base their decisions about care. Such research would also inform the debate around what outcomes are most appropriate to measure

and help develop consensus about recovery. Differences in approach adopted by services particularly relating to the level of control offered to individuals with AN and the role of a motivational based philosophy are likely to impact on outcomes. Research which examines differences in outcomes would provide information as to what aspects of service models would be most helpful in recovery from AN. Another area of research would be to examine the impacts of employing individuals with experience of AN gained either directly or through caring for someone with the disorder on the delivery of care and treatment. Such research would look at the impact of individuals with experience of AN on the perceptions and interventions carried out through involvement in the training and education initiatives for professionals. Another important aspect of such research would be to develop knowledge on how best to structure the delivery of such interventions and to support their delivery from these experts by experience.

Chapter 5 Reflexivity and reflections

In this section, I will outline my reflections on the research process and strive to reveal my role within it. The process has influenced me, those who participated, the environment in which I work as well as my life away from research and work. However, I will not address the final area listed and will contain my reflections mostly to the first two areas.

Reflexivity

'Reflexivity is a curious term with many meanings' (Dowling 2006, p.7) and has become important within the field of qualitative enquiry. Finlay (2002) has argued that it is an essential component of all types of research activity not only qualitative methods, without which validity would be undermined (p.453). In a later paper, Finlay (2006) argues that evaluating qualitative research against established criteria helps address criticism that it is a subjective account of the data and she lists reflexivity as one method of doing this. Koch & Harrington suggest that reflexivity, 'in all its guises' (p.888) has a central place in qualitative research where it is 'taking different forms and raising different questions' (p.888). Dowling (2006) sees reflexivity as a central concept and argues that it be 'viewed as a means of adding credibility' (p.70) a view shared with other authors. (Bradbury-Jones 2007, Baker 2006, Finlay 2006, Ballinger 2004, Wren 2004, Chiovitti & Piran 2003, Schutz 1994).

Thus, reflexivity adds to the trustworthiness of the findings of a qualitative study and it consists of a number of aspects. Holloway (2005) defines

reflexivity as being about 'the interaction of the researcher with the research and the participants as well as reciprocity between the researcher and the process of enquiry' (p.279). Wren (2004) suggests that reflexive researchers, 'whatever else they may be exploring or measuring - are also prepared to make their project itself an object of study' (p.476). The researcher turns a reflective but critical focus on themselves and the research project. Wren goes on to state that 'by doing so they (researchers) acknowledge that social science research is an 'interpretative activity'.

Yet a stance insisting on establishing rigour is more reminiscent of the positivist tradition and creates difficulties for a research paradigm, which acknowledges the possibility of many different interpretations of reality. (See Ballinger 2004, Koch & Harrington 1998). Indeed Schutz (1994) in an article exploring the benefits of a subjective approach in qualitative nursing research, argues that 'the transition to a more subjective and reflexive approach to nursing research may be painful but it brings benefits' (p.412). As an illustration of the difficulties that can exist between the applications of the two paradigms, Schutz (1994) makes the assertion that one of the benefits of the subjective approach is the 'eliciting of true meaning'. Such an outcome is more reminiscent of the claims of the quantitative paradigm in its pursuit of a single verifiable truth. As such, Holloway (2005) cautions researchers to avoid 'blurring the boundaries' (p.276) between the two research paradigms. Notwithstanding the claim made in the article, Schutz (1994) argues for the subjectivity of the researcher as an asset to the

project as opposed to undermining it through the introduction of bias. This is a theme picked up by many of the authors on writing about the importance of acknowledging the subjectivity of the researcher through reflexivity. (Bradbury-Jones 2007, Baker 2006, Finlay 2006, Ballinger 2004, Wren 2004, Chiovitti & Piran 2003).

As outlined in the introduction I share the view that the experience and knowledge brought to the research endeavour by the researcher is valuable. I believe it enables me to be more aware of what is happening in the data and as Wren (2004) states, 'Making sense of the kind of complex and often ambiguous responses typically generated by qualitative research involves active engagement with the data, in ways that can draw on clinical experience and sensitivity'(p.475). Also Strauss & Corbin (1990) refer to the concept of 'theoretical sensitivity' within the grounded theory method and describe it as an important component of the data analysis. Whilst doing so I was reflecting on the reasons for my choice of method and identifying how this choice set parameters for the study at the very start. Finlay (2006) in an article reflexively reviewing criteria for evaluating qualitative studies, reviews a number of frameworks through which evaluation can be done. She suggests that the different types of qualitative methodologies will affect the criteria chosen to evaluate them. Therefore, the reflexive researcher will choose criteria that reflect the assumptions made by their chosen method. Bradbury-Jones (2007) suggests that the qualitative researcher 'understands the ontological basis of their research to make explicit decisions made in terms of methodology and method'

(p.291). Such knowledge she argues enables the researcher to use these as a 'platform to research, analyse and make explicit their subjectivity' (p.291).

Types of reflexivity

Finlay (1998) differentiates between two types of reflexivity, which she labels '*methodological reflexivity*' and '*personal reflexivity*' (p.453 emphasis in the original). The first contains reflections on the method employed whilst the second contains reflections on the researcher's subjective responses within the research process. She goes on to note that the separation of the two can be problematic with overlap often occurring.

In her 2006 article, Finlay suggests that there are diverse terms used within the qualitative paradigm for evaluative purposes and that they often have similar meanings. Koch and Harrington (1998) when examining the concept of rigour identify four types of reflexivity, which they believe have a role to play in the reporting of qualitative studies. The first is similar to Finlay's personal reflexivity, as it has its focus the subjective and is concerned with the researcher's perspective. They caution, as does Holloway (2005), that this type of reflexivity is open to the charge of self-indulgence particularly if it has too narrowed a focus on the researcher's viewpoint. The risk is that the voice of the participants is overpowered by the voice of the researcher and lost. As a 'counter-practice' (p.888), Koch & Harrington (1998) suggest that, the researcher should incorporate many other influences and voices in their final report.

The second form of reflexivity identified by Koch & Harrington (1998) as a means of sustaining objectivity of demonstrating adherence to the method employed and resembles the methodological reflexivity suggested by Finlay (2006). For the authors this type of reflexivity has no overlap with the personal sphere and as such, it differs from Finlay's position that holds that some overlap can occur. A third type of reflexivity, referred to as the 'politics of location' (p.888) acknowledges the large number of possible interpretations of the data. Here the researcher is encouraged to reflect on not only their subjective position but also the many other interpretations that are possible. This also includes consideration of how the context of the research may influence the whole of the research process. Such awareness they argue, can contribute to the insights and critical appreciation of the research. A fourth type of reflexivity outlined by the authors is that of reflexivity from a 'feminist experiential standpoint' (p.888). Also referred to as 'positioning' (Dowling 2007) it has particular relevance to the reciprocal nature of the researcher-participant relationship. This view sees the researcher as unique and emphasises the collaborative nature of the research process with impacts in both directions. Thus, this type of reflexivity challenges the notion of an objective detached researcher. This view also places value on the knowledge and experience brought to the research by the researcher.

I employed each of the types of reflexivity within this thesis and outlined next are examples of this activity. Hand (2003) suggests that reflexivity should not only be a post hoc activity and that researchers should engage in reflexivity throughout the research process. One way I have done this is

to keep a research diary in which I have recorded my reflections about the process as they occurred. Also as I have been writing this thesis over an extended period of time I have outlined the various decisions I have taken as well as the reasons for them. I would suggest that different forms of reflexivity are more apparent at different stages of the process and this was the case for me. When I was deciding on the topic to research, I was reflecting on what I might study and the environment in which I would it carry out from both a personal and organisational standpoint. Whereas when I progressed to choosing the methodology my reflections had more to do with the methodological issues that I was likely to face. In agreement with Finlay (2006), I believe overlap is possible between the types of reflexivity as is clear from my reflections on using interviewing as my data collection technique. The methodological and subjective concerns that I had coalesced around my ability as an interviewer. The research interview and those, to which I am accustomed in my work as a nurse/therapist, are very different.

What follows next is an outline of some of my reflections on the research process. However, throughout this thesis I have recorded the circumstances of my decisions and the rationale behind them. Within the introduction and methodology chapters, there are a number of examples of reflexivity to which I would direct the reader. This is in line with the requirement that the research process be as transparent as possible for others to follow but also to reveal myself in the research. The choices which I made to exclude carers and focus groups from the study reflect my decision making when faced with the practical dilemmas in the process.

Other researchers could undoubtedly make different choices and this would be likely to alter the findings of the study.

Reflections on method

Another key decision point was the choosing of a qualitative methodology. In this study my aim was to explore the concept of recovery from AN from the perspective of those with experience of the disorder. I had worked in the field of eating disorders since 1991 and this had influenced me in many ways. My clinical experience had reflected a picture of treatment interventions with poor outcomes for those with AN as well as an often-strained relationship between those providing treatment and those receiving it. I was dissatisfied by this situation, this has influenced me in my professional development and in the way I have developed eating disorders service locally. I have adopted a philosophical approach that is important to acknowledge. The service does not provide treatment against the will of the individual with AN and seeks to negotiate treatment objectives in a collaborative manner which respects the autonomy of the person. The latter half of this philosophy is generally accepted with little argument but the former is not. I will not go into detail as to why this is the case but raise it here to provide the reader with context about one area in which I was researching and also to reveal my prejudice in my clinical practice. These are important in that they can influence the individuals with AN who chose to attend and then stay in such a service. This in turn will have an impact on the participants who are available to take part in the study. A countering factor to this possible bias was the recruitment of

participants from other services who do not have a similar philosophy to the local service in which I work.

In the literature which I had reviewed there was an absence of the perspective of those with AN about recovery from it. Therefore, I needed a research approach that enabled me to develop a deep appreciation of the concept of recovery from such a perspective. A methodology that did not require an established hypothesis to test but one which encouraged me to keep the themes emerging from participants accounts as the dominant data in the analysis. Alongside this, I hoped that the research would generate implications for clinical practice. I hoped that gaining a richer understanding of recovery from AN would lead to suggestions for change in my day-to-day clinical practice and that these would be shared with my colleagues. The existence of these motivations may be seen as benign in one sense but they influenced the research method I chose and continued to influence the data collection and analysis.

The methodology I chose, Grounded theory (Glaser & Strauss 1967) reflects these aims, with its emphasis on and specific procedures for the development of theory. If my research aim had been to describe the concept of recovery then my choice of methodology would have been different. During the study, I experienced a tension between the need to develop theory and my urge to describe what the participants were telling me. It seemed to me that in the act of developing theory I was distancing myself from the words of the participants and creating new concepts. I was

uneasy with such a development as I felt a strong commitment to report the story as described by participants. However, there were safeguards to help me with this tension. The constant return to the interview transcripts demanded by the method helped in keeping the participants words embedded in the new concepts. My decision to return to participants with the emerging theory not only addressed issues of rigour and trustworthiness but also reassured me that they recognised what was emerging. The comparison with the literature, both professional and that provided by individuals with experience of the disorder also help by confirming many aspects of study's findings. Given such support, I have taken the findings to my colleagues within the service and explored what we could do with them within our therapeutic programme. This has resulted in the development of a therapeutic group entitled, Recovering from AN, within our treatment programme. It has run for four cohorts of individuals and the feedback has been positive. A frequent comment has been that participants have not talked about recovery in this way previously rather the topic discussed with them has more often been treatment. This comment reveals a prejudice which can exist within the service models in place for those with eating disorders and which may be unintentionally limiting the possibilities for those with AN. I address this more within the implications section of the thesis.

Within qualitative research, there is an acknowledgement that the research endeavour is a joint undertaking between the researcher and the participants in which they co-create an understanding of the topic being

researched. As such, it is essential that care be taken to minimise any adverse impacts on both parties through the research process. This is usually achieved through the researcher reflecting on possible dangers and risks and then demonstrating how these will be addressed within an application for ethical approval. As I stated in the methodology I initially found this process cumbersome because of its bureaucratic demands but then came to value its contribution to the research process. It encouraged my concern for and commitment not to do harm to participants and guided me to consider areas that I would otherwise not have done. Alongside this, I am aware that the procedure if fully utilised will protect the researcher but on reflection, I did not give this sufficient attention.

I took steps to reduce the possibility of anyone feeling compelled to participate by virtue of being in treatment within the service, which I have outlined within the methodology section. Early participants came from within the inpatient arm of the service by virtue of being first to respond to the invitation to participate. Individuals in treatment with colleagues in the community arm of the service participated next. Such a variety I viewed as a strength of the study as any findings would incorporate both perspectives. However, as I reviewed later interview transcripts, comments about professionals involved in treatment were more frequent than previously. These comments were sometimes critical in nature and I wondered what might be happening. The first group of participants would have been more likely to know me as part of the treatment team that was caring for them whilst for later participants this was unlikely. I wondered if

indirectly my association with the inpatient treatment team had influenced those early participants in their responses. Further interviews were carried out outside of the service altogether. The participants also spoke about professionals and were critical of the input of those without knowledge and/or sympathy. Given the emergence of these themes in these two groups of participants, it is more likely that their absence in earlier interviews could have been due to fears about negative comments affecting people's treatment. As it turned out in this study, the remaining participants emerged from either, the community arm of the service or from out of the area covered by the service. However, I believe that research within a practice setting, as Butler pointed out, requires extra vigilance on the part of the researcher to minimise influencing the responses of participants. In future research, I would expend more effort in recruiting participants from outside of the service and would strive to recruit only new patients to the local service to reduce this bias.

My choice of the interview as the data collection method requires that a researcher and participant engage in a dialogue about a topic. They are both affected by what takes place; they cannot avoid having had the experience once they have taken part. Participants expressed surprise by the topic of the research but were pleased at the opportunity to discuss recovery. Those who were ill often had not considered some of the themes that arose in the interviews and as a result were responding to them for the first time. The effects of this are unpredictable. I had assumed that participants asked to speak about recovery from AN would be less likely to

experience harm from the interview than if they were discussing another aspect of their illness. I had arranged for support should distress arise because of the research. However, participants expressed fear and anxiety about the recovering process describing it as a difficult and demanding process. One outcome of this could be to decide not to recover or to become hopeless about the possibility of recovery. Although no participants described such an outcome and I received no feedback from the professionals involved in their care, it highlights an area that would need to be addressed in further work in this area. This may particularly be the case when an individual has had the AN for an extended period.

I was also surprised that participants had not discussed recovery before but maybe should not have been. The absence of this topic from the services within which I have worked reveals another prejudice about recovery in mental health now only being addressed. The recent Chief Nursing Officers for England (2005) report on mental health nursing specifically urges nurses to embrace the recovery model in their practice. This model differs from the traditional models in mental health care as can be seen from this quote from the service user organisation Rethink;

'Recovery can be defined as a personal process of tackling the adverse impacts of experiencing mental health problems, despite their continuing or long-term presence. It involves personal development and change, including acceptance there are problems to face, a sense of involvement and control over one's life, the cultivation of hope using support from others, including direct collaboration in joint problem

solving between people using services, workers and professionals. Recovery starts with the individual and works from the inside out. For this reason, it is personalised and challenges traditional approaches'. (Rethink 2005)

This quote captures the personal nature of recovery but it also highlights the significant demands of the recovering process, an emphasis not often found within the normative view of recovery that exists within the medical model. I was surprised by participant's perspective on recovery as a difficult, demanding and dangerous activity that could contribute to relapse. In interviews with individuals still ill with AN they shared the fears they had about recovery whilst those recovering described the hour-by-hour battle to sustain their commitment to recover. As a nurse my training had socialised me to perceive recovery as a, if not wholly positive process, then one that is worth it in the end. Individuals sometimes had to work hard to recover from illness and that there were often costs to be borne such as in the case of chemotherapy or radiotherapy. Yet I had not heard or read any stories about what I perceive as courageous work within the field of mental health. As I listened to the participants descriptions of recovery I became aware of just how hard it is to recover from AN and by extension from mental health problems. The stigma and prejudice that they experience increases the task and can undermine efforts at recovery.

My decision to interview those still ill with AN and not just those who were recovered also had a distinct impact on the research. These individual's

descriptions of their struggle with recovery including deciding to recover were particularly clear and conveyed their dilemma. They were questioning the utility of recovery because of their perception of both the benefits the AN brought and their fears about being able to manage the tasks of recovering. I found myself empathising with this perspective and at times reflecting on the hopelessness of the possibility of managing such a difficult task. Treatment interventions did not have a good outcome record and we know little about what treatments work for whom. At the same time these individuals could articulate what they anticipated would be the benefits of not having the AN. This ambivalence is characteristic of individuals with AN at times in their illness. What is clear from including those still ill is that they provided a powerful description of 'being in recovery' or recovering from AN which has informed the theory of recovery which emerged from the study. The similarities as well as the differences between their contribution and the contribution of those at other stages of recovery allowed these differing perceptions to be included and to inform the outcome. Without this breadth of experience, the influence of the active disorder on recovering would have been lost and it is likely that the findings could have been different.

Another area that warranted reflection on my part was the different roles I had and how these influenced the research process. I am a nurse, a therapist, the clinical lead to the service as well as a researcher. This history brings with it certain ways of being in the world, which will influence the research I undertake. I am a nurse by training and this has influenced

my focus on a holistic approach to the individual in need of care. However, this has been tempered and at times limited by the medical model in which I trained and initially worked. The momentum for this study emerged from my taking on the role of the consultant nurse, which amongst other things allowed me research time and removed operational management responsibilities from my role. Earlier I discussed how my significant role in developing the service has influenced its philosophy and as a result, how others perceive it. This 'insider status' is also likely to have impacted on my colleagues and their response to my requests for prospective participants. The steps I took in meeting with them and discussing the study whilst emphasising the voluntary nature of participation were designed to minimise any sense of compulsion they may have had to provide participants to me. However, I cannot ignore the possibility of such an impact.

In the methodology chapter, I listed the steps I took to reduce confusion for potential participants, which included excluding those I had been in contact with as a nurse or therapist. I also arranged interviews to take place in a non-clinical setting and undertook interviews on my allocated research day. Another step I took was to change the uniform I wore as nurse/therapist/clinical lead. My badge, shirt and if I was wearing one, a tie were removed and I adopted a more relaxed style of clothing to reflect my role as researcher. This served to prompt not only me, but also my colleagues that I was there to undertake research and not to address queries about the service. It also facilitated me in distancing myself from

the other roles I had of nurse or therapist within the service. These steps served to help me switch from my work role to the research role. I have argued earlier that my knowledge and skills are valuable aspects of the research process but I am not speaking here of bracketing my assumptions. I am speaking of reducing role confusion for both the participants and myself.

The above steps also helped me to address concerns I had about the research interviews evolving into therapy. I have outlined the steps I took before the interviews to set them up as research activities and again emphasised this in the interview proper with research participants. The tape recorder and microphone were also indicators to me that the interviews were separate from my clinical role, as we do not record clinical interviews within the service. However individuals shared with me their hopes and fears about their recovery or not, and I found it difficult not to engage in a dialogue which supported recovery. I worried that if someone expressed little or no hope as to recovery what my response would be and decided that I had to avoid becoming the therapist. Fortunately, this did not arise although how difficult the process of recovery was did. Perhaps as discussed in the introduction the fact that the topic was recovery from AN and my role as interested outsider combined to reduce the likelihood of such a response emerging.

A final dilemma for both the participants and me emerged from the differing roles I have and I believe it to be important. It relates to individuals who

took part in the study who were then readmitted to the service for treatment later. The dilemma for the individual was that I was a member of their treatment team by virtue of my role as a clinician in the service but they had talked to me previously as a researcher. As for me, I had excluded people with whom I had worked from the study because of concerns about dual roles and wondered how previous participation in research would influence my relationship with the individual. A separate but connected dilemma arose when an individual from out of the catchment area, who had participated in the study, was referred to me personally for an assessment. I discussed the broader dilemma with colleagues at work and my clinical supervisor before reaching the conclusion that I could not exclude myself from someone's care because they had participated in a research project. In addition, I had not included in my information sheet about the study any suggestion that future care could be compromised in any way by participation in the study. For the participants rather than assume that they would agree to this the team decided that another member of the team would ask any participant admitted about my involvement in their care and to respect their wishes. In the case of the personal referral to me, a similar approach was taken to ensure the individual was given the opportunity to proceed or not with the knowledge that I would be carrying out the assessment.

The emergence of these dilemmas highlights a difficulty in carrying out research in clinical settings by clinicians who continue to work in the settings. This is particularly so where individuals may return for treatment

after participation and where the participants are vulnerable which was the case here. It presents as the corollary of, do you undertake research with people you are directly involved with treating? Skårderud (2007) suggests that it is possible to do this and to resolve the tensions that exist between the roles of the clinician and researcher. He suggests that in studies where the aim is 'the patients improved self understanding and articulation of her situation' (p.166) there is no conflict as this is also the aim of therapy. He further suggests that the information the therapist brings to the research interview is important to the interpretations made and that the research interview be seen as an 'intersubjective co-construction of meaning' (p.166). Both of these resonate with the qualitative method and my own view of the value of experience and knowledge in the research setting. However, I cannot agree with his stance. He states that the research interview can become a channel of communication between the patient and the therapist, which to my mind blurs both the therapeutic and the research endeavour making it impossible to separate them out and decide what is being learned. He does not address the issue of power in the therapeutic relationship or how it could be addressed in the research context. The vulnerabilities of those engaged in therapy are not protected when the therapist has another motive for seeing them. This can be particularly true for those with AN who have been described as overly compliant and sensitive to the needs of others. Ensuring informed consent is also more complicated when engaging in research with those for whom you are also providing therapy. Therefore, I believe it is best not to undertake research with those to whom you are offering therapy.

In this section of my thesis, I have captured some of the key decision points and revealed both my decision-making and myself. I have also recorded the circumstances of the thesis and how they too have influenced the findings which have emerged. Perhaps the next set of reflections does not fit in this section but they are for me part of how the process has affected me as a researcher and a person carrying out research. The research process helped build my confidence academically and this influenced my clinical activity. I have read about, discussed and analysed more information than I care to recall in the completion of this project.

However, it has developed a confidence in defending my position with colleagues from other backgrounds who often appear more at ease with research and its uses. Previously I would not have done so or would not have taken the position in the first instance. Now the skills and knowledge acquired from this process serve as a toolbox I can draw on in dialogue with these colleagues that enables me to constructively present my case as well as provide evidence for it. Another effect has been that the world of research is now a reasonably friendly environment and I find myself looking for more research opportunities and encouraging others to do likewise. I have started another project employing quantitative methods and have secured funding for a research assistant to help with this. I do not think this would have been possible before. As important is that in carrying out the research interviews I have developed a greater awareness of the struggle for recovery which those with AN undergo. Only through the research process have I been able to appreciate this.

'The real voyage of discovery consists not in seeking new landscapes but in having new eyes' (Marcel Proust)

I have outlined the likelihood of the researcher being changed by their participation in the research process. The interaction with the other participants is not a one-way process and affects the researcher in a number of ways. Significantly, for me the quote above captures an influence participating in this study has had on me. The generosity shown by the participants in sharing their stories with a complete stranger despite their vulnerabilities was humbling. However more than this their desire and ability to communicate their situation was a powerful force, which enabled me to think outside of the theoretical models to which I had been socialised. I was helped to see with 'new eyes' experiences that I had observed previously through the eyes of a professional. This has altered my perspective on recovery and the need for it to have a much greater role in our service models. It has already contributed to change in my clinical practice and to how I acknowledge the struggle at the heart of recovery from AN. For these new eyes, I will be eternally grateful to the people who took part in the study and who also reminded me that I have much to learn from those who come in need of care.

Local ethics form and approval

East Dorset Local Research Ethics Committee

Our Ref: SW/RCH/LREC No: 1007/02/B

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e-mail: rhanson@poole-tr.swest.nhs.uk

Dear Mr Newell

Recovery in Anorexia Nervosa : A Q qualitative study of sufferers, those who have recovered and carer's views on what is important in recovery in Anorexia Nervosa
LREC NO : 1007/02/B [must be quoted in all correspondence]

The East Dorset Local Research Ethics Committee reviewed your application on 31 October 2002 and thanked you for your attendance. The documents reviewed were as follows:

Application Form, dated 1 October 2002
Letter in support of Application to Local Research Ethics Committee
Consent Form
Patient Information Sheet, dated 14 September 2002, version 3
Abbreviated CV
Protocol

The members of the Committee present agreed there is no objection on ethical grounds to the proposed study. I am therefore, happy to give you the favourable opinion of the Committee on the understanding that you will follow the conditions set out below:

Conditions

- You do not undertake this research in an NHS organisation until the relevant NHS management approval has been gained as set out in the *Framework for Research Governance in Health and Social Care*. →
- You do not deviate from, or make changes to, the protocol without prior written approval of the Research Ethics Committee, except where this is necessary to eliminate immediate hazards to research participants or when the change involves only logistical or administrative aspects of the research. In such cases the Research Ethics Committee should be informed within seven days of the implementation of the change.

Covering research in Bournemouth, Poole, Christchurch and surrounding areas

Chair: Stephanie Wheeler
Vice Chair: Richard Day

East Dorset Local Research Ethics Committee

Administrator: Rachael Hall
Poole Hospital NHS
Longfleet Road
Poole
Dorset
BH15 2AB

Tel: 01202 448111

Fax: 01202 448112

- You complete and return the standard progress report form to the Research Ethics Committee one year from the date on this letter and thereafter on an annual basis. This form should also be used to notify the Research Ethics Committee when your research is completed and in this case should be sent to this Research Ethics Committee within three months of completion.
- If you decided to terminate this research prematurely you send a report to this Research Ethics Committee within 15 days, indicating the reason for the early termination.
- You advise the Research Ethics Committee of any unusual or unexpected results that raise questions about the safety of the research.

The project must be started within three years of the date on this letter.

Present:	S Wheeler (Chair)	G P Clein	T Howard
	M Leggett	D Tory	B J Waltho
	S Elliott	P Leigh	D Jones

In Attendance: R Hanson, Administrator

Yours sincerely



Stephanie Wheeler
Chairman

EAST DORSET LOCAL RESEARCH ETHICS COMMITTEE

Covering research in Bournemouth, Poole, Christchurch and surrounding areas

Chair: Stephanie Wheeler

Vice Chair: Richard Day

Letter to support Application to Local Research Ethics Committee.

Consent.

As a senior Clinician within the field of eating disorders, I acknowledge that the matter of obtaining consent from participants must be addressed with great care and rigour. To ensure that participants freely take part the following steps will be taken:-

- a) None of the people invited will have been key-worked by the lead researcher.
- b) Prospective participants will receive a written invitation to participate which will include an information sheet about the study, and clear comments on the voluntary nature of participation.
- c) Participants will be made aware at each contact of their right to withdraw from the study without any consequences or need to give a reason. Consent will be confirmed at each contact. Consent will be recorded on tape during those sessions where recordings are made.
- d) If they return the consent form, only then will the Researcher contact them directly.

Possible Risks.

Individuals invited to reflect on their health, particularly their mental health, or that of close relatives, may experience distress. It is anticipated that as the focus is on the person's views on recovery, such a risk will be reduced but can not be removed completely. As an experienced therapist in this field I am aware of this risk and propose the following steps to address the risk.

- a) The initial step is ensuring voluntary participation, (see paragraph on consent).
- b) Interventions at the time guided by the individual's needs, including terminating the interview or participation in the group.
- c) Contact with a member of the Eating Disorders team will be offered, post participation in the interview and group to check for any delayed impact.
- d) Provision of contact numbers for local and national, user and carer support groups as alternatives to statutory sources of support.

Throughout the research process I anticipate employing my therapeutic skills to monitor impacts on participants and intervene as appropriate.

CIARÁN NEWELL
CONSULTANT NURSE.

ETHICS COMMITTEE APPLICATION FORM

For Ethics Committee use only

Number: Date received:

Outcome: Applicant informed:

INSTRUCTIONS: Please complete in typescript. Please select Yes/No options as appropriate. A version of this form is also available on disc in Word for Windows from the Ethics Committee Secretary.

It is essential that this form is completed fully and the relevant enclosures are received if the study is to receive proper scrutiny by the Ethics Committee. Please refer to the accompanying Guidance Notes when completing the form. Please complete the checklist before sending the form.

CHECKLIST

Please indicate if the following have been enclosed by selecting *Yes/No/Not applicable* options below. For details of the numbers of copies of the form and relevant enclosures required, please contact the relevant LREC secretary. (See Appendix 4 in the Guidance Notes for details.)

	Yes	No	Not applicable
_____ copies of application form (double-sided if possible)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____ copy/ies of protocol	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____ patient consent form(s)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____ patient information sheet(s)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____ GP/consultant information sheet(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
_____ copy/ies of lead applicant's CV on 2 sides A4 (Do not submit if already submitted in last 12 months.)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Questionnaire* <input type="checkbox"/> Finalised <input checked="" type="checkbox"/> Not yet finalised	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Copy of manufacturers data sheet for all drugs (one copy only)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Copy of investigators brochure (one copy only)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Copies of manufacturers indemnity (2 copies only)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Copy of CTX/CTL/DDX (one copy only)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Annexe A**	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Annexe B***	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Annexe C†	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

* Please indicate if not yet finalised. Include interview schedule if used.

** If the study involves the use of a new medicinal product or medical device, or the use of an existing product outside the terms of its product licence.

*** If the study includes the use of ionising or non-ionising radiation, radioactive substances or X Rays.

† For research in general practice.

Please indicate below to which LREC this application is to be submitted:

East Dorset Local Research Ethics Committee.

1. Short title of project (in not more than 6 words)

Recovery in Anorexia Nervosa(AN); Whats important?

Full title

Recovery in Anorexia Nervosa; A qualitative study of sufferers,

those who have recovered and carers views on what is important in.

recovery in Anorexia Nervosa(AN)

Summary of practical benefits/improvements in patient care which are envisaged

Highlight the participants views on what is important in recovery from

AN. Compare this with available outcome measures, develop a broader and richer understanding of recovery and use this to influence practice.

2. Applicant (All correspondence will be sent to this address unless indicated otherwise.)

Surname: Newell

Forename: Ciaran

Title: Mr.

Present appointment of applicant: Consultant Nurse, Eating Disorders service.

Qualifications: Registered Mental Nurse; B.A.(Hons) Psychology;

Diploma in Management studies; Diploma in Cognitive Behavioural Therapy.

Address: Kimmeridge Court Therapy Services,

69 Haven Road,

Canford Cliffs, Poole, Dorset.

BH13 7LN

Tel: 01202 492034

Fax: 01202 492019

Out of hours tel: 07880558274

Please note that a brief CV of head applicant must be attached with proposal (if one has not been submitted in the last 12 months). Please indicate relevant qualifications.

3. Other workers and departments/institutions involved

Study will be undertaken in collaboration with the Institute for Health and Community studies, Bournemouth University for the award of MPhil. The supervisory team appointed are Professor Peter Thomas, Dr. Les Todres and Professor Roger Baker.

4. Signature of relevant bodies

I undertake to carry out the work in accordance with the principles of the Declaration of Helsinki (copy available from the LREC secretary) and its amendments.

Signature of applicant..... Date.....

Signature of Head of Department/Supervisor/Principal in General Practice

with overall responsibility

for the project Date.....

NAME AND TITLE IN CAPITALS

I am fully aware of the details of this project and happy for it to continue as outlined here.

Signature(s) of relevant Clinical Director(s) where study is being conducted/Medical Director(s) signing on behalf of Trust(s) involved (where appropriate).

..... Date.....

NAME AND TITLE IN CAPITALS

8. Study design (e.g. cohort, case control)

Cohort study

9. i) How was the size of the study determined?

Willingness of target groups to participate. Participants had not had any treatment with researcher. Incidence of (AN) is low.

ii) Was there formal statistical input into the overall study design?

☐ Yes

☒ No

If Yes, please give name of adviser:

iii) What method of analysis will be used?

-systematic content analysis of the data from interviews and focus group transcriptions using grounded theory methodology.

10. Does the study fall into any of the following categories?

Pilot

☐ Yes

☐ No

Multi-centre study

☐ Yes

☐ No

Student project

☒ Yes

☐ No

If this is a multi-centre study, please complete the details below, otherwise go to Question 11.

i) Which centres are involved?

ii) Which ethics committees have been approached, and what is the outcome to date?

iii) Who will have overall responsibility for the study?

iv) Who has control of the data generated?

11. Where will the study take place and in what setting?

- interviews and focus groups in non-clinical settings;

12. Is any payment being made, or actively being sought by the investigator or department/unit in respect of this study (include research grants)?

☐ Yes

☒ No

If Yes, complete the section below; if No, go to Question 13.

i) Is the payment:

a) A block grant

☐ Yes

☒ No

If Yes, give details, including amount and source of funding

£

Name of funding body: _____

b) Based on the number of subjects recruited

☐ Yes

☐ No

If payment is based on number of subjects recruited (per capita/payment), state total sum payable for each subject completing the study.

£

State number of subjects agreed.

Will patients have their travel costs paid?

☐ Yes

☐ No

If multi-centre study, state total number of subjects to be recruited.

ii) Is the payment made in order to:

If Yes state sum

a) Pay a salary(ies)

☐ Yes

☐ No

£

b) Fund equipment

☐ Yes

☐ No

£

c) To support further departmental research

☐ Yes

☐ No

£

d) Other (state)

☐ Yes

☐ No

£

iii) Who will have control of the funds? eg Charitable Trust etc.

iv) Does the investigator(s) have any direct personal involvement (eg financial, share-holding etc.) in the sponsoring organisation? (If Yes, give details.)

☐ Yes

☒ No

v) Will all the costs incurred by the institution be covered by the grant?

☐ Yes

☐ No

13. If the project is to be carried out in a Trust has the R&D lead in the Trust been notified of the project?

If no/NA give reasons:

☒ Yes

☐ No

☐ NA

14. Schedule

Proposed starting date: October 2002

Proposed duration: 6-9 months

-
- 15. How will the patients or subjects in the study be selected, approached and recruited; what inclusion and exclusion criteria will be used? STATE IF THEY ARE THE SUBJECT OF THERAPEUTIC OR NON-THERAPEUTIC RESEARCH**

Participants will be, participating in NON-THERAPEUTIC research, sufferers of (AN) presently in treatment within Dorset Healthcare NHS trust Eating Disorders service, Past sufferers of (AN) treated by the service who identify themselves as recovered or carers of the above groups. All will be over 18.

Prospective participants will receive a letter containing, the details of the research project, what participation will involve, an emphasis on the voluntary nature of participation, notification of their right to terminate their involvement at any time without consequence and a consent form to sign.

- 16. How many subjects will be recruited and of what age group?**

Max of 4 in each group . Over 18 years of age. Not treated by the researcher.

- 17. How will the control group (if used) be selected, approached and recruited; what inclusion and exclusion criteria will be used? Type NA if no controls.**

N/A

- 18. How many controls will be recruited and of what age group?**

N/A

- 19. Are the subjects or controls included in this study involved in any other research investigation at the present time?**

☐ Yes ☐ No ☒ Not known

If Yes, please give details.

- 20. Will healthy volunteers be used?**

☐ Yes ☒ No

If Yes, complete details below. If No, go to Question 21.

i) What is their relationship to the investigator?

ii) Will they receive any payment, and if so, what is the source of that funding? ☐ Yes ☒ No

If Yes, give details of payment per subject.

Applicants should undertake to explain to volunteers that the researcher will contact their GP to ask about any drug therapy and that they must inform the researcher if they consult another doctor during the study, and that this doctor will be informed of this study.

21. Is written consent to be obtained?☒ Yes ☐ No

If Yes, please attach a copy of the consent form to be used.

(Guidance on consent is given in Appendices 1 and 3 in the Guidance Notes.)

If no written consent is to be obtained is it because one of the following methods of research is employed?

Postal questionnaire ☐ Yes ☐ NoInterview ☐ Yes ☐ NoOther ☐ Yes ☐ No

If Other, please justify.

22. Does the study include subjects for whom English is not a first language?☐ Yes ☒ No ☐ NA

If Yes give details of arrangement made; if No please justify.

23. Are the subjects or controls in one of the following vulnerable groups?Children under 16 ☐ Yes ☒ NoPeople with learning difficulties ☐ Yes ☒ NoOther vulnerable groups e.g. mental illness, dementia ☒ Yes ☐ No*If Yes, please complete the details below, otherwise go to Question 23.*

- i) What special arrangements have been made to deal with the issues of consent and assent, e.g. is parental or guardian agreement to be obtained, and if so in what form?

All participants will have written confirmation that taking part or not will have no impact on their treatment within the service and that they can withdraw their consent at any time without any impact on their own care or of their relatives in treatment.

- ii) In what way, if any, can the proposed study be expected to benefit the individual patient/subject on whom it is performed?

No direct benefit is claimed but participants will have the opportunity to articulate what is important to them about recovery from (AN).

24. Will the patient/subject be given a written information sheet or letter?*(For suggested format see Appendix 2 in Guidance Notes.)*☒ Yes ☐ No

If Yes, please attach copy to this application form.

If No, please justify.

25. Does the study involve the use of a new medicinal product or medical device, or the use of an existing product outside the terms of its product licence?

☐ Yes
☒ No

If Yes, please complete Annexe A in the Guidance Notes, otherwise go to Question 26.

26. Will any ionising or non-ionising radiation, or radioactive substances or X-Rays be administered to a patient or volunteer?

☐ Yes
☒ No

Please ensure information in Q14 includes exclusion criteria with regard to ionising radiation if appropriate.

If Yes, please complete Annexe B in the Guidance Notes, otherwise go to Question 27.

27. What investigations and/or interventions will subjects and/or controls have over and above routine care?
(Please complete the table below by selecting YES/NO options as appropriate. If YES, please give details.)

Investigation

Self completion questionnaires	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Interviews/interview administered questionnaires	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Interview administered questionnaires	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
Video/audio tape recording	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
Physical examination	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Internal physical examination	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Venepuncture*	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Arterial puncture*	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Biopsy material*	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Other tissue/body sample*	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Imaging investigations (<u>not radiation</u>)	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Other investigations not part of normal care	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Additional outpatients attendances	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Longer inpatient stays	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Local anaesthetic	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
General anaesthesia	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Other	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No

Details:

Focus group

* If yes, will samples be retained beyond the end of the study for testing for other factors beyond that in this proposal? ☐ Yes ☐ No

If yes, will samples be anonymised? ☐ Yes ☐ No

If no, please justify

If additional investigations or tests are involved with revenue consequences for the NHS the relevant head(s) of department(s) *must* be contacted.

Signature of Head of Department..... Date

NAME IN CAPITALS Position

28. Are there any ethical problems or considerations that the investigators consider to be important or difficult with the proposed study?

☒ Yes ☐ No

If Yes, please give details:

Vulnerable group of participants leading to issues around consent.

Clinician/researcher roles, possible conflict of interest and further issues around consent. See Q29, my covering letter and sampling methodology for steps to address these issues.

- 28a. Is it possible that the trial medication will not be available at the end of the trial?

☐ Yes ☐ No ☒ N/A

- 28b. If yes, is this made clear in the patient information sheet?

☐ Yes ☐ No

If No, give reasons

29. Are there any potential hazards to subjects or patients?

☒ Yes ☐ No

If Yes, please give details, and give the likelihood and details of precautions taken to meet them, and arrangements to deal with adverse events and overdoses, including reporting to the relevant authorities.

Some distress may arise in reflecting on their own or their relatives health. The likelihood is low.

If this occurs the lead researcher is an experienced clinician and will offer assistance at that time including terminating the participation in the interview/group. Should the participant wish to have a meeting with their key worker from the Eating Disorder service (EDS), past or present, this will be arranged. All participants will be offered the option of telephone contact by a member of the (EDS) 1-2 weeks post interview and group. This offer will be made at the end of EACH interview/group.

30. Is this study likely to cause discomfort or distress to subjects/patients?

☒ Yes ☐ No

If Yes, estimate the degree and likelihood of discomfort or distress entailed.

The degree and likelihood of distress differs amongst the participants but is low for all groups. See answer to question 29 for precautions to be taken to manage any distress that may arise.

31. Will information be given to the patient's General Practitioner (*especially* if a drug is to be given or an invasive procedure is undertaken)?

☐ Yes ☒ No

If *Yes*, please enclose an information sheet for the GP.

If *No*, please justify.

Not applicable

If the study is on hospital patients, has the consent of all consultants whose patients are involved in this research been obtained?

☒ Yes ☐ No

If the study is in general practice, has the consent of all the partners been obtained?

☐ Yes ☐ No

Where available, please enclose an information sheet for consultants or GPs.

Product liability and consumer protection legislation make the supplier and producer (manufacturer) or any person changing the nature of a substance, e.g. by dilution, strictly liable for any harm resulting from a consumer's (subject or patient) use of a product.

32. i) If you are not a member of staff of an NHS Trust or Health Authority what arrangements have been made to provide indemnification and/or compensation in the event of a claim by, or on behalf of, a subject for negligent harm?

ii) What arrangements have been made to provide indemnification and/or compensation in the event of a claim by, or on behalf of, a subject for non-negligent harm?

If applicable, the arrangements involving a drug supplied by a company should conform to the most recent ABPI guidelines on patient indemnity or individual Trust documents.

iii) Will a medical student be involved directly in the project?

☐ Yes ☒ No

33. Has a manufacturer provided any equipment or medical devices?
(Please indicate NA if not applicable.)

☐ Yes ☐ No ☒ NA

If Yes, what arrangements have been made with the manufacturer to provide indemnity?

34. i) Has the relevant Data Protection Officer been notified of the study? ☒ Yes ☐ No

Give name of Data Protection Officer: Andrew Betteridge.

iii) If No, give reasons

35. Will the patient's medical records be examined?

☐ Yes ☒ No

If Yes, will information relevant to this study only be extracted

☐ Yes ☒ No

If extra information is extracted, please justify.

What, if any, additional steps have been taken to safeguard confidentiality of personal records?

36. Will the study include the use of any of the following?

Audio/video tape recording

☒ Yes ☐ No

Observation of patients

☐ Yes ☒ No

If Yes to either,

a) How are confidentiality and anonymity to be ensured?

Interview and focus group tape recordings will be kept in a locked cabinet. Use of participant numbers in transcripts. Transcription will be undertaken by a secretary subject to the clause of confidentiality within trust contract. All personal identities will be made anonymous. Tapes and transcriptions will be kept secure in a locked cupboard at the Eating Disorder Service base on the St. Anns hospital site.

b) What arrangements have been made to obtain consent?

Prospective participants will be invited to participate via a letter outlining the details of the study including the use of audio taping. Consent will be sought and recorded at each interview and at the start of each group on tape.

c) What will happen to the tapes at the end of the study?

They will be kept secure at the Eating Disorder Service base at St. Anns hospital. After 5 years they will be destroyed. An article will be submitted for publication and it is a requirement of many journals that raw data is retained for 5 years.

37. Will medical records be examined by research worker(s) outside the employment of the NIIS?

☐ Yes ☒ No

If Yes, it is the responsibility of the principal investigator to ensure that research workers understand that they must:

- i) undertake never to divulge information about patients or research subjects, recorded or otherwise, to anyone without the authority of the Consultant/GP under whose care the patient is;
- ii) also understand that the names, addresses and places of work of patients or research subjects are confidential and must not be divulged.

Please ensure that you complete the check list on the front cover of the application form and enclose all relevant enclosures.

Appendix B

Study information sheet

Recovery in Anorexia Nervosa: What do sufferers and those who have recovered think is important?

Researcher; Ciarán Newell

You are being invited to take part in a research project. Here is some information to help you decide whether or not to take part. Please take time to read the following information carefully and discuss it with your friends, relatives and your G.P. if you wish. Ask me if there is anything you do not understand, or if you would like more information. Take time to decide whether or not you wish to take part. Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy can be obtained from CERES, P.O. Box 1365, London N16 0BW. Thank you for reading this.

What is the purpose of study?

The main aim of this study is to explore the individual views of sufferers and those who are recovered on what they believe to be important in recovery from Anorexia Nervosa (AN). Research into outcomes in (AN) has been undertaken, but the focus has often been placed on physical measures e.g. weight. It is hoped the study will identify other measures, which will give a richer understanding of recovery from this illness. The study will compare the groups with each other, as well as with present research in this area, identifying similarities and differences if they exist.

The study is being undertaken by Ciarán Newell a part of a DPhil Degree at the Institute of Health and Community Studies of Bournemouth University. The part of the project in which you are being invited to participate, will take place between October 2005 and August 2006.

Why have I been chosen?

You have been invited to participate because one or more of the following criteria apply to you;

- A. You suffer from Anorexia Nervosa (AN)
- B. You have suffered from (AN), but now identify yourself as recovered.
- C. You are over the age of 18.
- D. Have or have had contact with the local Eating Disorders Service.
- E. The lead researcher has not been your key-worker

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you should keep this information sheet, sign and return the consent form. A copy of this will be given to you to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive from the Eating Disorder service.

What will happen to me if I do take part?

The researcher would like to invite you to participate in an interview. The interview will last between 45 minutes and one hour. You will be asked questions relating to the aims of the study stated above. The interview will take place at a location you find convenient and comfortable. The interview will be recorded on to audiotape as part of the research. The researcher may request a follow up meeting to check with you that what has come out of the interview is what you wish to say.

It is difficult to know for sure how a person might respond to discussing issues important to their health. In this study the focus is on what you see as important in recovery from Anorexia Nervosa. There is a risk that you could become upset by recollection of information about your health you are using to inform the view you want to take now. Should this happen, the following assistance will be available: -

- a) The lead researcher is an experienced clinician/therapist and will offer support and intervention at the time, including terminating the interview.
- b) Alternatively, or as well, if you have an identified key worker, a meeting with them will be arranged. (If you have previously had a key-worker in the Eating Disorder Service, contact with them will be arranged.)
- c) Contact numbers for voluntary sector organisations who provide support and advice for those affected by an eating disorder will also be made available.

What do I have to do?

There are not any special requirements of you.

What are the possible disadvantages and risks of taking part?

The only risk that can be foreseen is the one mentioned previously: that you may become upset by recollections of events relating to your health. The steps mentioned above are designed to assist you should this happen

What are the possible benefits of taking part?

Although participating in the study will not be of any clinical benefit to you, the information you provide the researcher with may help the treatment of others with anorexia nervosa in the future.

Will my taking part in this study be kept confidential?

All information, which is collected, about you during the course of the research will be kept strictly confidential. Any information about you will have your name and address removed so that you cannot

be recognised from it. The tape recordings and transcripts will be kept in a locked cupboard at the Eating Disorders service base. The researcher may include quotes of what you have said in the report, but will make sure that you cannot be recognised from these. Many journals require that tapes and transcripts are kept secure for 5 years, after which time they will be destroyed.

What will happen to the results of the study?

The study will be completed by September 2007 and a copy will be available to you on request from the researcher. An article will also be submitted for publication. You will not be identified in the report.

Who is organising and funding the research?

This study is part of the researcher's job. As such the main funding comes from the National Health Service via Dorset HealthCare NHS Trust, the researcher's employer.

Who has reviewed the Study?

The East Dorset Local Research Ethics Committee has reviewed the study and decided that it addresses the ethical issues, particularly risk or harm to participants, as well as its scientific merit.

CONTACT FOR FURTHER INFORMATION: -

Ciarán Newell,
Consultant Nurse,
C/o Kimmeridge Court,
69 Haven Road,
Canford Cliffs,
Poole,
Dorset.
BH13 7LN

Tel: 01202 492034 Fax: 01202492019
Email: ciaran.newell@dorsethc-tr.swest.nhs.uk

Thank you for participating in the study.

11.08.2005 version 7

Appendix C

Study consent form

Participant Number:

CONSENT FORM.

Title of Project: Recovery in Anorexia Nervosa: What do sufferers and those who have recovered think is important?

Name of Researcher: Ciarán Newell

		Please initial Box
1	I confirm that I have read and understood the information sheet dated 10.08.2005(version 7) for the above study and have had the opportunity to ask questions	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, without my medical care or legal rights being affected.	
3	I agree to take part in an interview.	
4	I agree to the interview being tape recorded.	

.....
Name of Participant

.....
Date

.....
Signature

.....
Name of Person taking
Consent (if different
From researcher)

.....
Date

.....
Signature

.....
Researcher

.....
Date

.....
Signature

Participant Number:

CONSENT FORM.

Title of Project: Recovery in Anorexia Nervosa: What do sufferers, those who have recovered and carers think is important?

Name of Researcher: Ciarán Newell

		Please initial Box
1	I confirm that I have read and understood the information sheet dated 11.02.2004(version 6) for the above study and have had the opportunity to ask questions	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, without my medical care or legal rights being affected.	
3	I agree to take part in an interview.	
4	I agree to the interview being tape recorded.	

.....
Name of Participant

.....
Date

.....
Signature

.....
Name of Person taking
Consent (if different
From researcher)

.....
Date

.....
Signature

.....
Researcher

.....
Date

.....
Signature

Appendix D

Ethics amendment forms



Dorset Research Ethics Committee (REC)

Our Ref: 1007/02/B

1 March 2004

Poole Hospital NHS Trust
D Block [Eddie Hawker Wing], Room 20
Longfleet Road
Poole, Dorset
BH15 2JB

Ciaran Newell
Consultant Nurse Eating Disorders Service
Kimmeridge Court Therapy Service
St Anns Hospital
69 Haven Road
Canford Cliffs
Poole BH13 7LN

Tel: 01202 448 201
Fax: 01202 442 954

Dear Mr Newell

LREC 1007/02/B

Recovery in anorexia nervosa : a qualitative study of sufferers, those who have recovered and carers views on what is important in recovery in anorexia nervosa

Thank you for the protocol amendment:

Removal of Focus Group
Patient Information Sheet version 6 dated 11.2.2004

Sent to the Dorset Research Ethics Committee. This was recently considered at the meeting of 26 February 2004 by the Committee and was noted for information and approved.

Should members raise any further issues I will advise you in due course.

Present at the Meeting :

Ms S Wheeler, Chair
Mr M Leggett
Mrs S Elliot
Dr B Quilty
Observer:
In Attendance :

Dr R Day, Vice Chair
Ms L A Wareing
Dr J Begley
Dr A J Williams
Julia Marsden, Pre Reg Pharmacist
R Hanson, Administrator

Dr D Jones, 2nd Vice Chair
Ms F Cowdell
Ms B J Waltho
Dr P Leigh
Dr T Howard

Yours sincerely

RACHAEL HANSON
ADMINISTRATOR, DORSET RESEARCH ETHICS COMMITTEE

EAST DORSET LOCAL RESEARCH ETHICS COMMITTEE

AMENDMENT APPROVAL REQUEST FORM

To be completed by the principal researcher or sponsor company on behalf of the principal researcher and submitted to the appropriate REC.

Name & Address of Principal Researcher: Ciarán Newell, Kimmeridge Court
Therapy Service, 69 Haven Rd.
Canford Cliffs, Poole Dorset.

Full Title of Study: Recovery in Anorexia Nervosa; A qualitative
study of sufferers, those who have recovered and carers views
on what is important in recovery in Anorexia Nervosa (AN)

LREC No and Version Number:

1007/02/B

Drug Company Protocol No. [if applicable]:

Amendment Number & Date:

1 Proposed 11/02/04.

Information about the amendment: 1) It is proposed to remove the
focus group component of the study.

1. Is the amendment purely administrative? YES ☒ NO NA

2. Has the Patient Information Sheet/Consent Form been changed as a result of the Amendment?

☒ YES NO NA

If yes, please enclose a copy.

3. Has this amendment been submitted to the Medicines Control Agency?

YES NO ☒ NA

4. Has the Medicines Control Agency approved the amendment?

YES NO ☒ NA

If no, please state the reason.

5. Summarise the issues contained in the amendment.
Underline the amendment where appropriate.

1) Feedback from supervisor and colleagues suggested
that having the focus group was a disincentive for
proposed participants. (Colleagues who were providing
details to proposed participants whilst supervisor was
offering feedback on his experience.)

2) Concern that this was adversely affecting recruitment.



Dorset Research Ethics Committee (REC)

Poole Hospital NHS Trust
D Block [Eddie Hawker Wing], Room 20
Longfleet Road
Poole, Dorset
BH15 2JB

RH/MY

4 November 2005

Tel: 01202 448 201
Fax: 01202 442 954

Mr Ciaran Newell
Kimmeridge Court Therapy Service
69 Haven Road
Canford Cliffs
Poole,
BH13 7LN

Dear Mr Newell

Study Title: Recovery in Anorexia Nervosa (AN); What is Important?
REC reference:1007/02/B

Thank you for letting us know of the recent alterations in your research. This has been reviewed by the Committee at their meeting on the 13th October 05.

1007/02/B	Please quote this number on all correspondence
-----------	--

Yours sincerely

Rachael Hanson
Committee Administrator

E-mail: Rachael.hanson@poole.nhs.uk

Copy to D



East Somerset Local Research Ethics Committee
Research & Development Department
Level 4
Yeovil District Hospital
Higher Kingston
YEovil
Somerset BA21 4AT

15 APR 2004

Tel: 01935 384615
Fax: 01935 384653

Our Ref: JM/nm/mar242

8th April 2004

Mr Claran Newell
Consultant Nurse
Dorset Healthcare NHS Trust
Kimmeridge Court
St Ann's Hospital
69 Haven Road, Canford Cliffs
Poole, BH13 7LN

Dear Mr Newell

Full title of study: Recovery in Anorexia Nervosa: A qualitative study of sufferers, those who have recovered and carers views on what is important in recovery in Anorexia Nervosa
REC reference number: 04/Q2203/4

Thank you for your application to conduct the above research as Chief Investigator for East Somerset NHS Trust. I can confirm that the application was received on 5th April 2004.

An assessment of the suitability of the local investigator(s), support staff, site and facilities will be made by the Local Research Ethics Committee. We will notify the main Research Ethics Committee, Dorset Local Research Ethics Committee, within 30 days of receiving your application whether or not there is any objection to the research being conducted locally.

It is your responsibility to ensure you have final management approval from the host organisation before commencing any research procedures.

Yours sincerely

N.A. Marks.

Mrs Nicky Marks
Administrator

*cc'd
Deirdre Sparrowhawk
Les Tades*



Central Office for Research Ethics Committees (COREC)

Room 76, B Block
40 Eastbourne Terrace
London W2 3QR

Tel: 020 7725 3431
Fax: 020 7725 3465

Website: www.corec.org.uk

Our Ref: JW/013/EE

Mrs Rachel Hanson
Dorset LREC
Poole Hospital NHS Trust
Room 20, D Block
Longfleet Road
Poole, BH15 2JB

2nd April 2004

Dear Mrs Hanson,

Re: Study Reference: 1007/02/B

Recovery in Anorexia Nervosa: A qualitative study of sufferers, those who have recovered and carers views on what is important in recovery in Anorexia Nervosa.

The above study originally received a favourable opinion from Dorset REC. The Chief Investigator now wants to add a second site at East Somerset LREC.

In order to manage this process within our new SOPs I am appointing Dorset as the main REC. All amendments need only be reported to Dorset. In order for the SSA to be managed using the database I would be grateful if you could enter the Reference Number, CI details and title on RED.

When the SSA is completed at East Somerset they will notify you if they have 'no objection'. You should then inform the CI using the interim letter attached as a template (copy will follow by e-mail).

Please do not hesitate to contact me if you require clarification on any of the above.

Yours sincerely

**Dr Janet Wisely
Director of Corporate Affairs
Central Office for Research Ethics Committees (COREC)**

cc. Ms Nicky Marks, East Somerset LREC
Mr Ciaran Newell, Chief Investigator

03 JUN 2004



Dorset Research Ethics Committee (REC)

Poole Hospital NHS Trust
D Block [Eddie Hawker Wing], Room 20
Longfleet Road
Poole, Dorset
BH15 2JB

27 May 2004

Mr Ciaran Newell
Consultant Nurse Eating Disorders Service
Kimmeridge Court Therapy Service
St Anns Hospital
69 Haven Road
Canford Cliffs
Poole BH13 7LN

Tel: 01202 448 201
Fax: 01202 442 954

Dear Mr Newell

Full title of Study: Recovery in Anorexia Nervosa: a qualitative study of sufferers, those who have recovered and carers views on what is important in recovery in anorexia nervosa

Old LREC Reference: 1007/02/B

New REC Number: 04/Q2201/8

SSA Reference: East Somerset 04/Q2203/4

An assessment of the suitability of the investigator, site and facilities has been made by East Somerset Local Research Ethics Committee.

The details of the site are as follows:

Principal Investigator: Mr Ciaran Newell
Research site: Somerset Partnership NHS Trust

We have received written notification from the assessor there is no objection to the research being conducted on the above site.

Yours sincerely,

Rachael Hanson
Dorset REC Administrator

NHS Research Ethics Committee

APPLICATION FORM

PART C: SITE-SPECIFIC ASSESSMENT

This form should be completed by the Principal Investigator for each site (see glossary)

Part C should be completed and sent with relevant enclosures to each NHS Research Ethics Committee or Research & Development (R&D) department which needs to consider site-specific issues. Consult the application procedure on the COREC website.

The data in this box is populated from Part A.

Name of NHS Research Ethics Committee to which application for ethical review is being made:

East Dorset

Project Reference number from above REC: 1007/02/B

Name of site NHS REC (or R&D department) undertaking site-specific assessment:

East Somerset local Research Ethics committee.

Site NHS REC (or R&D Department) Identifier:

Questions C1, C4, C5, C6, C7 and C8 correspond to questions A1, A2, A65, A10, A12 and A13 on main application form respectively and will populate automatically:

C1. Title of Research. (Populated from A1)

Full title: Recovery in Anorexia Nervosa; A qualitative study of sufferers, those who have recovered and carers views on what is important in recovery in Anorexia Nervosa(AN).

Key words: Recovery, Sufferers Recovered individuals, Carers, Perspectives, Anorexia Nervosa, Grounded theory.

C2. Who is the Principal Investigator for this study at this site?

Title: mr First Name/Initials: ciaran Last Name: newell

Post: consultant Nurse

Qualifications: RMN. BA(hons) Diploma CBT. Diploma Management

Organisation: Dorset Healthcare NHS Trust

Address: 69 Haven Road , Canford Cliffs,
Poole
Dorset

Postcode: BH13 7 LN

Email: ciaran.newell@dorsethc-tr.swest.nhs.uk

Telephone: 01202 492147

Fax: 01202 492019

A copy of a current CV (maximum 2 pages of A4) for the Principal Investigator(s) must be submitted with application.

C3. Indicate the number of trials/projects within the organisation that the local Principal Investigator has been involved with in the previous 12 months:

How many are still current (active or recruiting)?

Give details of other members of the local research team responsible to the local Principal Investigator

- i** Title: First Name/Initials Last Name:
 Position:
 Qualifications:
 Role in the research team:
- ii** Title: First Name/Initials Last Name:
 Position:
 Qualifications:
 Role in the research team:
- iii** Title: First Name/Initials Last Name:
 Position:
 Qualifications:
 Role in the research team:

If there are more members of the local research team, details should be provided at question C18 or on an attached sheet.

C4. Chief Investigator. (Populated from A2)

Title: MR First Name/Initials: Ciaran Last Name: Newell
 Post: Consultant Nurse Eating Disorders.
 Qualifications RMN. BA(hons). DIP(CBT) DIP(management)
 Organisation: Dorset healthcare trust.
 Address: Kimmeridge Court, 69 Haven Road, Canford Cliffs, Poole.
 Dorset
 Postcode: BH13 7LN
 Email: ciaran.newell@dorsethc-tr.swest.nhs.uk
 Telephone: 01202 492147
 Fax: 01202 492019

C5. Other relevant reference numbers if known: (Populated from A65)

Applicant's/organisation's own reference number, e.g. R&D (if available):

DHC-02-007 (R&D)

Sponsor's/protocol number:

Funder's reference number:

International Standard Randomized Controlled Trial Number:(ISRCTN):

European Clinical Trials Database (EUDRACT) Number:

Project website:

C6. Give a brief synopsis/summary of methods and overview of the planned research. This should include a brief description of how prospective research participants and concerned communities (not necessarily geographical) from which they are drawn have been consulted over the design and details of the research. (Where appropriate a flow chart or diagram should be submitted separately. It should be clear exactly what will happen to the research participant, how many times and in what order.) (Populated from A10.)

A Grounded Theory approach will be employed to ensure that any theory that is developed will arise from the data and reflect the participants perspective on recovery.

A purposive sample of 4 present sufferers, 4 recovered individuals and 4 carers will be identified. The sample was chosen on the following grounds, incidence of (AN) is low, the willingness of target groups to participate and that participants had not had any treatment with principal investigator who has been a major provider of treatment and care in the local area.

Participants will be invited to participate in an interview which will last between 30 minutes and an hour and a half to explore the research questions. Interviews will take place in settings that are convenient for participants.

Data from each interview will be recorded, transcribed and a systematic content analysis undertaken to identify important themes and new questions to be employed with further interviews either with other participants or with the participant who gave the interview to clarify and to check that they accurately reflect their perspective. The important themes that arise will undergo constant comparison with the literature to identify relevant theory if available. If not then new theory will be developed.

The principal investigator will maintain a diary throughout the research process to record impacts on the researcher in line with the demands of the methodology.

**PAGE
NUMBERING
AS ORIGINAL**

C7. Will the research participants receive any clinical intervention(s) or procedure(s) including taking samples of human biological material over and above that which would normally be considered a part of routine clinical care? (Populated from A12)

YES ☐

NO ☒

C8. Will the research participant be subject to any non-clinical research-related intervention(s) or procedure(s)? (Populated from A13)				
YES <input checked="" type="checkbox"/> NO <input type="checkbox"/>				
Additional intervention	Average number per patient		Average time taken (mins/hrs /days)	Details of additional intervention or procedure, who will undertake it, and what training they have received.
	Routine Care	Research		
Face to Face Interview		1	45mins	Principal invstigator will share a 1:1 interview with the participant utilising a topic guide, to cover the topics to inform the research question. Clinician of 12 years experience with Psychiatric nurse training, training in Cognitive Behavioural therapy,motivational interviewing and counselling skills.
Audio recording		1	45mins	audio taping of thr interview for transcription and analysis.Principal investigator.
Please give details for other(s):				

C9. Name of NIIS or other organisation where the research will take place.

Somerset Partnership NHS TRust.

C10. Specify the location(s)/department(s) within the NIIS or other organisation where the research will take place.

To be confirmed but most likely within the eating disorders department space. It is the intention of the investigator to give participants choice in where the interview takes place.

C11. How many research participants/samples is it anticipated will be recruited/obtained from this organisation in total?

6

C12. Give details of who will be responsible for obtaining informed consent locally, their qualifications and relevant expertise and training in obtaining consent for research purposes:

principal investigator.

C13. What local arrangements have been made for participants who might not adequately understand verbal explanations or written information given in English? (e.g. translation, use of interpreters etc.)

The purposeful sampling method will preclude such participants due to the demands of the research.

C14. What arrangements have been made to inform those responsible for the care of the research participants of their involvement in the research?

Mostly they will be the local collaborators in the Eating disorders service for the project and will therefore be identifying prospective participants from within their service. It is also suggested to participants that they discuss participation with their GP in the information leaflet that is supplied to them.

C15. Are the facilities and staffing available locally adequate to perform any necessary procedures or interventions required for the study, and to deal with any unforeseen consequences of these? (This should include consideration of procedures and interventions in both control and intervention arms of a study.)

YES ☒

NO ☐

Give the information necessary to justify your answer:

The local service collaborators have agreed to provide appointments to participants should one be required. They have no other role to play.

C16. Give details of a contact point where participants may obtain further information about the study.

Ciaran Newell 01020492034

Please specify the headed paper to be used for the information sheet.

Dorset Healthcare NHS Trust.

C17. If there is no Principal Investigator at local level, is there a local individual who is undertaking a task relating to the research?

YES ☐

NO ☐ Not Applicable ☒

C18. Do you need to add further information about certain questions in Part C?

YES ☐

NO ☒

Part C: Declaration

- The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
- I undertake to abide by the ethical principles underpinning the Declaration of Helsinki, and Good Practice Guidelines on current proper conduct of research.
- If the research is approved I undertake to adhere to the study protocol without unagreed deviation and to comply with any conditions set out in the letter sent by the NHS Research Ethics Committee notifying me of this.
- I undertake to inform the NHS Research Ethics Committee of any changes in the protocol, and to submit annual reports setting out the progress of the research.
- I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer.
- I understand that research records/data may be subject to inspection for audit purposes if required in future.
- I understand that personal data about me as a researcher in this application will be held by the Research Ethics Committee and its operational managers, and that this will be managed according to the principles established in the Data Protection Act.

Signature of the local Principal Investigator*

Signature

Date:

Print Name:

* The Chief Investigator should sign where there is no local Principal Investigator for the research locality.

PART C IS NOW COMPLETE AND SHOULD BE SUBMITTED to the NHS Research Ethics Committee or NHS organisation conducting site-specific assessment

Appendix E

Research permission in second location



Somerset Partnership

NHS and Social Care Trust



Broadway House
Broadway Park
Barclay Street
Bridgwater
Somerset
TA6 5YA

Tel: 01278-720209

Fax: 01278-720201

Our Ref: TA/dmg

12th 2004

Mr Ciáran Newell
Consultant Nurse
c/o Kimmeridge Court
69 Haven Road
Canford Cliffs
Poole
Dorset BH13 7LN

14 MAY 2004

Dear Ciáran

Re: Study Into Patient Carers Perception of Recovery of Anorexia Nervosa

Thank you for your correspondence in respect of the above which I have now had opportunity to share broadly through the service and can reassure you that the Somerset Partnership will support your proposed research project.

Effectively I believe that this response is sufficient for the East Somerset Ethical approval although they may require me, as a nominated Research Lead, to actually sign your LREC application form, which of course I will be happy to do so.

Although I am the nominated lead for research for the Somerset Partnership, on a practical day to day basis Ruth Halsey, Professional Head of Nursing/Assistant Director of Nursing would be far easier to contact and be in a position to offer you any practical support that you may need. As a consequence I have copied her into this letter and the information that you sent me in respect of your proposed research project.

It was good to see you at the Executive Nurse Forum and looking so well, I hope to see you again in the near future. I would certainly appreciate an opportunity to see your research findings.

Yours sincerely


TIM ARCHER

Director of Nursing & Services
for Adults and Young People

Copy to: Ruth Halsey



Dear Tim,

Re. Local R&D approval for study into patient and carers perception of recovery in Anorexia Nervosa.

My name is Ciaran Newell and I am Consultant Nurse in Eating Disorders in Dorset and it is in that capacity that I think we have met. I am writing to you in your capacity as lead for R&D for the Partnership trust to seek approval to recruit participants for the study mentioned above from people in contact with the local eating disorders service. This study is part of my MPhil study programme. I have received ethical approval from the East Dorset LREC. A condition of this is that I should not interview anyone with whom I have had clinical contact this has the effect of reducing the small group of possible participants available in Dorset further and making recruitment more difficult than anticipated.

In discussion with my supervisor at Bournemouth University, whose research committee have also approved the study, I was encouraged to seek participants in other areas. I have had informal discussions with colleagues in the Eating Disorders service in Somerset and they were supportive of the proposal and believed that there are possible participants. One colleague, Duncan Churchill-Moss, discussed it with his manager Sue Flynn and Mr. James Marriott. I telephoned the latter at Duncan's suggestion, and he kindly informed me of the process I would need to follow and of his support for the proposal.

I have begun the process of obtaining Site Specific Assessment from the East Somerset LREC as required under the new Research Governance arrangements and I am in contact with Nicky Marks the administrator. Nicky informed me that local R&D approval was also necessary. I enclose with this letter documents outlining the proposal, what is required of participants and samples of the leaflets that participants will receive.

I would be most grateful if you could deal with this within your systems and let me know the outcome. Should you require any further information please do not hesitate to contact me.

Yours Sincerely

Ciarán Newell

Appendix F

Original interview guide

INTERVIEW OUTLINE

- Briefing
- Introduction – thank them
 - Have they any questions before we start?
 - Define situation:

- a) Purpose of interview
- b) Use of tape recorder
- c) Importance of their views
- d) Revisit consent.

- Interaction
- *Switch on tape recorder*
 - *Confirm consent from participant*

- A. When you hear the words "Recovery from Anorexia Nervosa" (RFAN) what springs to mind?

Listen for key words/phrases

Seek further information

Can you say more about

- B. Thank you for that. When others hear those words "RFAN" what do you believe springs to their minds?

- C. Have you discussed recovery with others. If so could you share your thoughts on this?

How would you describe others' ideas about recovery?

Are they similar or different to yours for example?

Check if any questions; are they still comfortable?

- D. Would you say your ideas about RFAN have changed over time?. If so could you say something about how they have changed.

- E. How would you describe your role in "RFAN"?

Can you say more about that?

- F. How would you describe the role of others in RFAN?

- G. From what you have said their role would appear to be distinct from yours. Can you say more about that?

What are their contributions?

INTERVIEW OUTLINE

() Participant 342 – Recovered.

- Briefing
- Introduction – thank them
 - Have they any questions before we start?
 - Define situation:
 - a) Purpose of interview
 - b) Use of tape recorder
 - c) Importance of their views
 - d) Revisit consent.

- Interaction
- *Switch of tape recorder*
 - *Confirm consent from participant*

A. When you hear the words “Recovery from Anorexia Nervosa” (RFAN) what springs to mind?

Listen for key words/phrases

Seek further information

Can you say more about

B. Thank you for that. When others hear those words “RFAN” what do you believe springs to their minds?

Partners

Relatives

Friends

Professionals

Church

Parents

Children

From what you say they appear to differ from yours. Would you say they differ from yours?

C. Have you discussed recovery with others who were ill. If so could you share your thoughts on this?

How would you describe others’ ideas about recovery?

Are they similar or different to yours for example?

Check if any questions; are they still comfortable?

D. Would you say your ideas about RFAN have changed over time?. If so could you say something about how they have changed.

E. How would you describe your role in "RFAN"?

Can you say more about that?

F. How would you describe the role of others in RFAN?

Partners, parents, friends?

G. From what you have said their role would appear to be distinct from yours.

Can you say more about that?

What are their contributions?

H. In your opinion if asked to choose what is important to RFAN – what might you include?

I. What are your thoughts on whether others are necessary for recover?

J. Thank you. I have no further questions. Was there anything you would like to add, anything you wanted to say but you have not been asked? Anything you want to bring up before we finish the interview?

K. *Reflect back on some of the ideas, emphasise first impressions and seek feedback?*

Switch off tape recorder.

DEBRIEF

Thank participant.

How was it?

Inform participant of next steps?

Copy of transcribed interview? Yes/No

Possibility of follow-up to check on accuracy of my understanding.

Any questions, queries contact researcher.

End interview.

Allow 10 minutes to reflect on interview to record impressions on tape.

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